The Whole and the Parts: Spiritual Aspects of Care in a West of Scotland Hospice

Bella Vivat

PhD

the University of Edinburgh

2004

This thesis has been composed by me and is entirely my own work

For my mother

ABSTRACT

This thesis is an exploration of the spiritual aspects of hospice care, framed by my understanding of various sociologies and philosophies of knowledge, and particular interest in how people implement theories, beliefs and knowledges, especially excluded knowledges, in practice. The study examines the relationship between the dominant understandings and structures of allopathic medicine, the claim that hospices provide "total" or "holistic" care (which includes spiritual care) for dying people, and the practices of workers in a particular hospice. In addition, it considers the relevance for my own research practice of feminist research methodologies and the attempt to integrate ways of knowing which are considered, on the one hand, "emotional" and/or "subjective," and, on the other hand, "rational" and/or "objective."

The thesis begins with a chapter which considers the various arguments for the social construction of knowledge, focusing predominantly on Thomas Kuhn's concept of the "disciplinary matrix," and discussing its relationship to new, particularly challenging theories, such as the theory of social construction of knowledge itself and Cicely Saunders' theory of "total pain" and "total care." The thesis proceeds to outline my methodological approach, using feminist ethnographic methods, and to discuss my approach to analysis. This chapter is followed by two chapters which discuss my empirical findings. The first of these two chapters, drawing predominantly on material gathered through participant observation, reflects upon general aspects of care in the hospice, and notes the difficulties of observing spiritual aspects of care. The second empirical chapter considers workers' perceptions and talk about these particular aspects of care, primarily through the material I gathered through one-to-one interviews.

I argue that the particular hospice I studied was not a uniform place, but rather an assembly of distinct spaces, and workers' practices differed both between these different parts of the hospice and between workers within each area. Thus, there was not a uniform approach to care in the hospice, and it varied depending on which particular workers were involved with a particular patient. Most workers were nevertheless aware of, and often claimed to adhere to, the hospice philosophy of holistic or total care, and many identified the spiritual aspects of care as the most important aspects of hospice care. Yet these particular aspects of care were those which, it seemed to me, were most frequently absent; in part owing to the variation in workers' perceptions and practices. Few workers in the hospice identified a spiritual aspect to the care which they personally

gave, feeling that spiritual aspects of care were part of "somebody else's job." Of those few workers who identified a spiritual aspect to the care which they gave, most located this in their attitude towards the patients. However, a few workers in this small group considered that spiritual care involved both a particular attitude on the part of the carer and also a particular content: explicit engagement with questions which may be termed spiritual, metaphysical, existential and/or religious, an understanding of spiritual care which is, I suggest, closest to that of Cicely Saunders.

Thus, although workers were aware of the philosophy of total care, they generally perceived total care as being the outcome of all the activities performed by all the members of the multi-disciplinary team. Workers' practices were shaped more by their disciplinary backgrounds, and the associated structures of professional health care, than by the philosophy of total care. The net result was that spiritual care was often absent, since few workers identified providing this care as part of their role, but assigned it to an indefinite other member of the multi-disciplinary team.

I conclude by referring back to the situatedness of knowledges and practices, and the complex relation between knowledges and practices, and by pointing to the difficulties of implementing radically new or challenging theories, beliefs and knowledges in practice, both for workers in the hospice which I studied and also for myself.

CONTENTS

Acknowledgments	**iv**
Chapter 1: Introduction	**1-12**
Chapter 2: Situated knowledges in theory and practice	**13-92**
Chapter 3: Methodology and analysis	**93-156**
Chapter 4: Location and movement in St Z's	**157-240**
Chapter 5: Spiritual aspects of care in St Z's	**241-294**
Chapter 6: Discussion and conclusion	**295-350**
Bibliography	**351-394**
Appendix I: Letter requesting access	**395**
Appendix II: Research information sheet	**396**
Appendix III: Consent form	**397**
Appendix IV: Codes for and brief biographies of workers	**398-400**
Appendix V: Transcript notation	**401-402**
Appendix VI: Situated ethics and feminist ethnography in a West of Scotland hospice	**403-413**

ACKNOWLEDGMENTS

The first group of people I would like to acknowledge are of course people in "St Z's," both workers and patients, during my fieldwork in 1998-9. I am grateful to them for the welcome they gave to me, and for their openness and kindness at all times.

Secondly, many people have helped me directly or have contributed in other ways to the writing of this thesis. First, of course, I would like to thank my supervisors: Professor Liz Bondi and Dr Steve Tilley. I am also grateful to Dr Steve Sturdy and Dr Wendy Faulkner from the Science Studies Unit, both of whom provided supervisory input at various times. Dr Sturdy also provided additional advice and assistance on several occasions, which I greatly valued, and for which I thank him.

Several postgraduate students from the Science Studies Unit also helped me in writing this thesis, and/or simply in surviving the process, most particularly Patricia Soley y Beltrán, Massimo Mazzotti, and Matthias Klaes. I would also like to thank those other Edinburgh postgraduates who were part of my life while studying for this thesis: Judith Mónica Sanchez y Flores, Caitlin Scott, and all the members of the Feminist Geography Reading Group 1998-2000.

Last, but certainly not least, I am grateful to the Economic and Social Research Council for funding this study.

- 1 -

INTRODUCTION

My thesis is an exploration of the relationship between the practices of workers in a particular hospice, "St Z's," and Cicely Saunders' theory of "total pain" and "total care"[1] (which, for convenience, I contract to "total pain/care"). In parallel to this, I also seek to investigate the relationship between theory and practice for myself, that is, in my attempt to be an "engaged" social researcher.

My thesis consists of six chapters; this introductory chapter and five chapters following from it. The current chapter outlines and briefly discusses the content of each chapter that follows. In the next chapter, chapter two, I consider the background to my project: the interweavings between the claim that knowledge is a social and cultural product, my personal interest in this claim, and the relationship between these and the theory of total pain/care which is claimed to be the distinctive feature of hospice care. In chapter three I discuss being in St Z's; I outline my methodology – how I did my fieldwork – and consider particular issues which arise relating to thinking, analysing and writing about it. In chapter four I draw on material from my participant observation, aiming to give a sense of the general context of my fieldwork, examining the differences and similarities between parts of St Z's, and between the workers and patients in these different places. In chapter five I draw on material from the interviews which I conducted with workers in St Z's, and discuss the perceptions of spirituality and the spiritual aspects of care of some of these workers. In chapter six I reflect upon the consequences of my research findings for the questions with which I began, and discuss the relationship between these and the theoretical perspectives I outline in chapter two. I conclude by considering issues which arise when applying radical new theories in practice, in relation both to St Z's and to my work on St Z's.

---

[1] Cicely M Saunders (1984b), 'The philosophy of terminal care,' pp. 232-41 in Saunders, CM (ed.), *The Management of Terminal Malignant Disease,* 2nd edition. London: Edward Arnold.

My thesis is unavoidably constructed in a linear fashion, but this does not reflect how it developed. In particular, my understanding of the different perspectives on the theory of the social construction of knowledge developed in parallel with my experiences of and reflections on my fieldwork. I went to St Z's with the feeling that there was something important about the relationship between spirituality and health care which related to how allopathic medical knowledge is constructed. However, at the time of doing my fieldwork this was only an intuition; I had not, and could not have, formulated it in the way in which it now stands. So, although in the physical format of my thesis my theoretical chapter (chapter two) precedes my empirical chapters (chapters four and five), these three chapters were in fact written in tandem.

My reflections on my observations and discussions with people in the hospice fed back into my understanding of the field of social constructivism, and also stimulated my search for other perspectives which provided other insights into what I was observing and thinking. This occurred both while I was doing my fieldwork and also subsequently when I came to write my thesis. I drafted and then outlined chapters two, four and five simultaneously, so when I wrote chapter two I had already begun writing chapters four and five, and I wrote chapter two with the main issues which I aimed to discuss in these later chapters in mind. Likewise, when I wrote the empirical chapters (chapters four and five) I was holding the theoretical framework I had begun to outline in chapter two in mind. I continued writing and rewriting all of these chapters in dialogue with one another.

Thus, despite what the order of my chapters might suggest, I did not establish a theory prior to going to the field which then framed my perceptions of what happened there. I constructed my theory chapter in relation to my empirical chapters, and my theoretical position emerged in tandem with my empirical findings. Similarly, as I discuss in chapter three, analysis was not something which I did after having collected my data, but was an iterative process which took place alongside and through my fieldwork. Thus, my theory, fieldwork and analysis developed simultaneously, not

sequentially. Crucially, I began this project expecting to end it having attempted to describe the spiritual aspects of care. However, as I discuss throughout my thesis, as my fieldwork proceeded, I became increasingly uncertain whether I was observing such aspects of care, not least because few workers identified them as occurring in St Z's. My project thus changed to one of describing/explaining how it seemed to me that such aspects of care were largely absent in St Z's.

Chapter two: Situated knowledges in theory and practice

Since my work is cross-disciplinary and draws on multiple fields I did not conduct a literature review *per se*. I did not aim to identify every text in every related field but instead tried to identify texts from each field which are both key texts and relate to the themes in which I am interested, seeking to make interconnections between those which I have identified as particularly relevant, in particular that of "situatedness,"[2] both in relation to myself as a situated researcher and also in relation to how beliefs, theories, knowledges and practices more generally are themselves situated. I therefore begin chapter two by outlining my personal journey to this point – how I came to be here doing this – and throughout the chapter I trace my developing understanding, using this as a framework for discussing various perspectives on knowledge, in particular those of Thomas Kuhn[3] and Ludwik Fleck;[4] developments of these by the "sociology of scientific knowledge" or "SSK;" and the arguments put forward by feminist and/or postcolonial theorists of knowledge, who I term "engaged social constructivists."

I end this chapter with the point where my theoretical explorations ended, which was where I had begun, but now with a new perspective. In particular, I discuss my

---

[2] Donna Haraway (1988), 'Situated knowledges: the science question in feminism and the privilege of partial perspective', *Feminist Studies*, 14 (3): 575-99.
[3] Thomas S Kuhn (1962; 2nd edition 1969), *The Structure of Scientific Revolutions*. Chicago: University of Chicago Press.
[4] Ludwik Fleck (1935; 1979, edited by Thaddeus J Trenn and Robert K Merton; translated by Fred Bradley and Thaddeus J Trenn), *Genesis and Development of a Scientific Fact*. Chicago and London: University of Chicago Press.

reading of Kuhn's elaboration of the concept of "paradigm" (in the sense of a "world view") into what he called the "disciplinary matrix" of a disciplinary community (or, in Fleck's terms, a "thought collective"). Kuhn argued that members of a disciplinary (scientific) community share what he called a disciplinary matrix, which he defined as a constellation of beliefs, values and techniques. Each disciplinary matrix has four components: paradigms (in the limited sense of examples of problem solutions); symbolic generalisations (formulae or equations); values; and metaphysical paradigms (which, to reduce confusion, I call metaphysical models). I will suggest that new and radical theories, such as social constructivism itself, and also Cicely Saunders' theory of total pain/care, have particular consequences for the values and metaphysical models of disciplinary matrices, and that people may therefore "conventionalise"[5] such theories in terms of their pre-existing understandings.

Throughout my thesis I use the term "allopathic medicine" to describe the particular body of knowledge which is variously called Western medicine, scientific medicine, biomedicine, or allopathic medicine. This is because I find the other terms more problematic, for the following reasons. First, even apart from difficulties in defining "Western" and "the West," "Western medicine" is not only practised in "the West," but is practised and taught internationally. Second, as Sandra Harding, amongst many others, argues,[6] the term "scientific medicine" is problematic, owing to its links to the problematic questions of what science is, and what is scientific. Finally, the term "biomedicine," used, for example, by Margaret Stacey[7] (again, among others), could imply that other systems of knowledge about health and the body do not relate to biological understandings. In contrast, many Indians use the term "allopathic" (from the Greek *allos*: other) to distinguish this particular body of knowledge from others, such as

[5] David Bloor (1997), 'Remember the strong programme?' *Science, Technology and Human Values*, 22: 373-85: 375, drawing on Frederic C Bartlett (1932), *Remembering: A Study in Experimental and Social Psychology*. Cambridge: Cambridge University Press.
[6] Sandra Harding (1998), *Is Science Multicultural? Postcolonialisms, Feminisms and Epistemologies*. Bloomington, Ind: Indiana University Press.
[7] Margaret Stacey (1988), *The Sociology of Health and Healing: A Textbook*. London: Unwin Hyman.

homeopathic (from the Greek *homeo*: same) and Ayurvedic medicines, which have their own understandings of the body, biology and health care. I also like the sense of othering which the term "allopathy" carries, because it conveys a strong sense of the body being perceived as separate from "the person," "the mind," or "the self," which is characteristic of this particular body of knowledge.

In the 1960s Cicely Saunders and others established St Christopher's Hospice in South London.[8] They drew on the long-established tradition of hospices, developing this in conjunction with the systematic study of pain relief, alongside new pharmaceutical developments, of opioids, in particular. The aim was explicitly reformist: to create an institution which had an explicitly different approach to the care of dying people from that of allopathic medicine.[9]

I argue that both engaged social constructivists and the founders of the modern hospice movement share a similar disquiet, relating to the sense that "something is missing" from dominant understandings. For feminist and/or postcolonial epistemologists, something is missing from the dominant definition of knowledge, something which relates to issues of subjectivity, emotion, and other excluded knowledges, concepts and understandings. For Cicely Saunders and the other pioneers of the modern hospice movement, something was missing from the allopathic medical concept of health, illness and disease, particularly in relation to the needs of dying people. Thus, for me there was potentially an appealing symmetry between how I sought to approach this study and what I was seeking to study. For both, I was asking what happens when people try to replace the thing they perceive to be missing. It seems to me that people try to do this in one of two ways, which can be summarised as "reform" or

[7] Margaret Stacey (1988), *The Sociology of Health and Healing: A Textbook.* London: Unwin Hyman.
[8] Shirley du Boulay (1984), *Cicely Saunders: The Founder of the Modern Hospice Movement.* London: Hodder and Stoughton.
[9] Cicely Saunders (1981), 'The founding philosophy,' p. 4 in Saunders, C, Summers, DH and N Teller (eds.), *Hospice: The Living Idea.* London: Edward Arnold.

"revolt." That is, on the one hand, "add <*the missing thing*> and stir" it into existing practices, and, on the other, establish an entirely new way of doing things. [10]

Chapter three: Methodology and analysis

In chapter three I consider the methodology which I used for my fieldwork. I briefly describe St Z's and outline the detail of the activities I engaged in at St Z's. I consider issues for writing fieldnotes and conducting interviews, for leaving "the field," for analysing my findings and for writing ethnography. Through all of this runs an awareness of the reciprocity of my participant observation. As E Stina Lyon and Joan Busfield say, reflexive research, and the changes in conceptions of researcher and researched which are associated with it – such that 'the researcher is not a privileged investigator but an enquiring participant' – implies greater reciprocity between researcher and researched. They argue that 'the ethical and political responsibilities in doing research deepens with such reciprocity,' and so the researcher needs to develop humility and self-awareness.[11] This is perhaps particularly the case when researching topics such as spirituality, which themselves relate to vulnerability, humility and self-awareness.

A key aspect of the situatedness of my thesis is that it, like any ethnography, is an historical document. It is therefore my picture of a particular hospice at a particular point in time, when a particular group of people, with whom my relationships varied, were working, living and dying there. This particularity is accentuated because my fieldwork at St Z's occurred at a time when major changes were taking place in the hospice. The organisation of wards changed significantly, by the end of my fieldwork

[10] On this debate in relation to "add women and stir," see Maria Mies (1983), 'Towards a methodology for feminist research,' pp. 117-39 in Bowles, G and RD Klein (eds.), *Theories of Women's Studies*. London: Routledge and Kegan Paul (later republished pp. 64-82 in Hammersley, M (ed.) (1993), *Social Research: Philosophy, Politics and Practice*. London, Newbury Park: Sage).

[11] E Stina Lyon and Joan Busfield (1996), 'Introduction,' in Lyon, ES and J Busfield (eds.), *Methodological Imaginations*. London and Basingstoke: Macmillan, xv. See my discussion of the ethics of research in Vivat (2002), 'Situated ethics and feminist ethnography in a West of Scotland hospice,' pp.

the number of palliative care patients had almost doubled, and the number of elderly care patients almost halved. This had consequences for staff, some of whom had to change the wards they worked on, and, therefore, their working practices. Additional staff were also taken on, including a second medical consultant (Dr 21) and a pastoral care co-ordinator (PCC 24), both of whom had explicit understandings of and attitudes towards spiritual care. All these factors underline that my thesis is a partial, historical picture (although it may still be possible to make connections with wider issues and themes).

A particular issue for partiality is that my thesis lacks taped interviews with patients. My main focus is on workers, that is, people who have not received a terminal diagnosis, whose presence in the hospice is ongoing, not temporary, and this may seem strange in a study of hospice. However, workers were as much part of St Z's as patients were. Further, I focused predominantly on workers' perceptions and did not interview patients for ethical reasons, which I discuss both in chapter five, and elsewhere.[12] I suggest, however, that my thesis is no less interesting for the absence of patients' perceptions, although patients' perspectives are of course crucial, and further research in this area is important.

The absence of patients' perceptions adds to the sense in which my thesis is about absences. In the most obvious sense, it marks the absence of all the palliative care patients I discuss, who have all died since I conducted my fieldwork several years ago. Secondly, as I have said, any detailed discussion of their voices is absent. And third, as I conclude, specifically spiritual aspects of care were largely absent in St Z's.

Chapter four: Location and movement in St Z's

In chapter four I will discuss my sense that patients came to one of three distinct places in St Z's: day care, the elderly care ward ("St E's"), or the palliative care ward ("St P's").

236-52 in Bondi, L et al, *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research*. Lanham, Maryland, and Oxford: Rowman and Littlefield (Appendix VI).

[12] Vivat, op. cit., note 11.

In each place was a particular combination of workers (waged staff and volunteers), and, related to this, each place was associated with patients who were perceived as having particular needs, which were addressed by the particular group of workers who worked in that place. Thus, there were marked differences across St Z's, and I therefore argue that in this sense it was not a single place, but rather a collection of places. Yet there were common features across St Z's, precisely *because* these different parts of St Z's were so distinct.

One such common feature was the importance which people (both workers and patients) attached to the particular place in St Z's where patients were physically located, and, if or when patients were moved between places, to where they were moved from, and where to. Patients' physical location and movement was associated with their perceived "closeness" to death, and this metaphorical understanding was echoed in the metaphorical language which people in St Z's used to anticipate and predict patients' deaths. They spoke of people who they perceived as likely to die in the "near" future as "going down" or "going downhill." Thus, I will argue, people in St Z's, particularly workers, constructed death as metaphorically elsewhere – DOWN – and patients were physically moved and located in particular places in association with how far "down" workers perceived them to be. If at all possible, workers put patients who were perceived as "going down/hill" in single rooms, and so death and dying were generally located in private spaces. Talk about death and dying was also generally located in particular, also private, places; such conversation was rare in shared, public spaces, and workers and most patients were uncomfortable when it happened.

Lakoff and Johnson discuss metaphorical understandings of abstract concepts, and in their consideration of "orientational metaphors" they focus particularly on the metaphoric pair: UP-DOWN.[13] Lakoff and Johnson argue that all DOWN metaphors have

[13] George Lakoff and Mark Johnson (1980), *Metaphors We Live By*. Chicago and London: University of Chicago Press.

particular negative associations, and I will claim that this seemed to be evident in relation to "going down/hill" for people in St Z's.

Chapter five: Spiritual aspects of care

So death and dying, and talk about death and dying, were privatised in St Z's, seldom occurring in public, shared spaces. Paradoxically, perhaps, this individualised understanding of death and dying was shared across St Z's; that is, there was a *collective* understanding of death and dying as private, individual events. A similar situation existed in relation to the spiritual aspects of care, whereby talk about "Why me?" questions, which I relate to such aspects of care, did not occur in public spaces. Thus, the absence of patients' perspectives on spiritual care in this thesis parallels the absence of such perspectives in public spaces in St Z's.

In chapter five I discuss how most workers in St Z's said that they did not know what the spiritual aspects of care were, nor could they identify any workers who they felt provided such aspects of care. Few workers claimed that they personally provided such care (and this contributed to my ethical uncertainty concerning interviewing patients about spiritual care). Of the few (seven or eight) workers who claimed that they did provide spiritual care, or had some understanding of what it was, one said that it related to her attitude towards the people she cared for. The other workers in this small group talked of spiritual care as involving more than an attitude, relating to a particular action on their part, that is, "getting deeper" with a patient. I will discuss how I relate these two perceptions – of spiritual care as an attitude or an action – to the distinction between instrumental care (that is, care with a particular content; *what* is done) and expressive care (that is, care which is given in a particular manner; *how* it is done).

Thus, those people who I identify as having an instrumental, active understanding of spiritual care constructed spirituality as elsewhere: DEEP. Since spirituality was (metaphorically) elsewhere, action, or (metaphoric) movement – "getting deeper" – was necessary to reach it. This movement involved work, and required effort, in part because

"getting deep" exposed the vulnerability of both people. As one nurse commented: "as you get deeper it gets harder." There are parallels and echoes between this metaphorical understanding of spirituality as elsewhere, that is, DEEP, and how people in St Z's metaphorically constructed death as elsewhere, that is, DOWN. DOWN and DEEP are conceptually linked, and I will suggest that workers' difficulties with "getting deep" were perhaps, at least in part, associated with the negative connotations of DOWN.

Chapter six: Discussion and conclusion

I conclude my thesis by discussing my findings in relation to the theoretical positions which I outline in chapter two. I began with an interest in the relationship between the theory of total pain/care and the practices of workers in St Z's, and I found that workers in St Z's were aware of the hospice movement's philosophy of holistic or total care, and of its argument that all aspects of care are interwoven. However, the way in which St Z's was structured led to the separation of the various aspects of care. Different "kinds" of patients were located in different parts of St Z's, and identified as having different needs, which required different kinds of care, provided by different members of the multi-disciplinary team ("MDT").

Thus, for most workers in St Z's, "total" or "holistic" care meant that the whole person (patient) was cared for by the whole MDT, not by a single person (worker). That is, workers perceived that total care of each patient was the outcome of a group of people working together to address the various needs of that individual. For them, the "whole" of holistic or total care was the sum of the parts; each worker had their particular role in the provision of total care.

I will argue that this sense of the division of labour between workers was linked to the question of expertise. Workers in St Z's were very conscious of their job boundaries – what they could and could not do (in the sense both of being able to do something and being permitted to do something). Because most workers did not have an understanding of spiritual care, and because (unlike other kinds of care) it was the

specific responsibility of no particular worker, workers either autonomously claimed it and took it on as their task or (more often) did not do so, because they felt unqualified.

Chris Argyris and Donald Schön[14] distinguish between people's "espoused" theories and their "theories-in-use," and I will argue that workers in St Z's can be thought of as "espousing" the theory of total pain/care. That is, workers in St Z's subscribed to the idea that people have spiritual selves as well as physical, social and psychological (mental) selves, and some workers stated that spiritual care was the most important aspect of care; patients' other needs should be addressed in order to clear a way to engage with their spiritual concerns. However the actual practice (the "theory-in-use") of most workers in St Z's often led to the inversion of this. Workers most often acted in accordance with the conventional division of labour along professional lines which occurs elsewhere in organised allopathic medical health care systems. The result was that the primary/initial focus of the MDT was physical care, followed by psychosocial care (which for some workers, particularly nurses, perhaps occurred in tandem with physical care), with spiritual care coming last, if at all. As one interviewee told me: "being is what you do when all the doing is done."

I will end by returning to discuss the metaphysical model of allopathic medicine, and its conceptualisation of a person as an assembly of body, plus mind, plus (perhaps) spirit. Biopsychosocial care is modelled along these lines, and arguably reproduces this understanding of a person as being a collection of parts, although it claims to integrate the parts of a person. The multidisciplinary health care team reflects this metaphysical model: a collection of people, from different disciplines, who focus on different things and have different responsibilities (since it only makes sense to divide up needs, and the associated responsibilities to address them, if they are conceptualised as separate and divisible). In contrast, compare the metaphysical models of traditional Chinese medicine or Ayurvedic medicine, where spirituality is there from the beginning, conceptualised as inseparably part of a person, and so part of any health care they may receive.

[14] Chris Argyris and Donald A Schön (1974), *Theory in Practice*. San Francisco: Jossey-Bass.

In 1992, Nicky James and David Field expressed the concern that the assimilation of hospices into the allopathic medical mainstream could result in the "routinisation" of hospice care.[15] I will claim that, rather than this routinisation of care, my findings (in 1998) illustrate how people conventionalise a radical theory to fit with their disciplinary matrices, including their metaphysical models.

I end by discussing the implications of my findings, in relation both to the practices of workers in St Z's and to my own research practice. In terms of my wider question of whether it is possible to "add spirituality and stir," I will suggest that people need to keep sight of the broader aims of radical, fundamental changes in theories, if such theories are not to be conventionalised within existing, dominant understandings.

[15] Nicky James and David Field (1992), 'The routinization of hospice: charisma and bureaucratisation,' *Social Science and Medicine*, 34 (12): 1363-75.

- 2 -

SITUATED KNOWLEDGES IN THEORY AND PRACTICE

> 'Dear me, what nonsense all this is!' he said, and turned his back on the demons. They stopped abruptly and looked confused. [...] For some moments he regarded the smoky, luridly sombre view. Then: 'I don't believe it,' he said, quietly. [...] The ground trembled a little under their feet. Mr Watts drew a deep breath. 'I don't believe it!' he said, loudly. There was a loud crack [...] The ground shook violently. [...] There was a roaring and a crashing and a hissing of steam all around them, and through it Mr Watts' voice bawled again: 'I DON'T BELIEVE IT!'
>
> "Confidence trick," John Wyndham[1]

INTRODUCTION

In this chapter I shall outline various positions on the social construction of knowledge, and indicate how these link to my study. I am particularly interested in the relationship between theories and practices, and in this thesis I will consider this on two levels. My main focus is on the understandings and practices of the workers in "St Z's" (the hospice where I conducted my fieldwork), in relation to Cicely Saunders' theory of "total pain/care."[2] On a second level, I am seeking to investigate the relationship between the theory of the social construction of knowledge and my own research practice and production of knowledge (that is, this thesis). In relation to the latter point, this chapter partly serves to retrace my movement through the field of science studies, and so it "situates" my own knowledge,[3] and models the reflexive position which I have taken, which I discuss later in the chapter.

---

[1] John Wyndham (1974), 'Confidence trick,' pp. 119-35 in *Jizzle*. London: New England Press: 130-1. The character of Christopher Watts is a scientist, who holds that: "The consolidation of society on faith, irrespective of scientific truth, is the method of a Stalin' (133). However, as I shall argue, scientific truth is itself consolidated on faith, and, just as hell (and, later, the City of London) collapses in response to Christopher Watts' "I don't believe it," so too scientific theories collapse if scientists withdraw their belief in them.

[2] Cicely M Saunders (1984b), 'The philosophy of terminal care,' pp. 232-41 in Saunders, CM (ed. 2nd edition), *The Management of Terminal Malignant Disease*. London: Edward Arnold.

[3] Donna Haraway (1988), 'Situated knowledges: the science question in feminism and the privilege of partial perspective', *Feminist Studies*, 14 (3): 575-99.

I will begin the chapter by outlining how I came to the field of the social construction of knowledge, and then proceed to consider various positions within this field, beginning by focusing on the work of Thomas Kuhn,[4] and pointing out parallels between this and the earlier work of Ludwik Fleck.[5] I will be predominantly referring to studies which focus on science rather than allopathic medicine, but, as Ludwik Fleck pointed out in the 1930s, there are significant parallels between how people construct and produce scientific knowledge and how they construct and produce allopathic medical knowledge (which seeks and claims to be scientific). My main focus at this point in the chapter is on Kuhn's discussion of how scientists learn science, and the implications of this process for "scientific revolutions" (his term for scientists' changes of theories), and for scientists' movement from espousing an existing theory to fully accepting a new one.

I then proceed to discuss the sociology of scientific knowledge (SSK) and the various debates between proponents of the theory of the social construction of knowledge, highlighting those aspects which, prior to beginning my fieldwork, I felt were likely to be relevant to my fieldwork findings. These include discussions concerning the disunity of science, and the field of science as practice. I also detail aspects of debates around explanation or description, the positions of various postcolonial and feminist theorists, and issues around the questions of reflexivity and relativism and excluded knowledges, tracing how these relate to my approach to my fieldwork.

The positions and understandings which I outline in this first part of the chapter are those of which I was aware when I began my fieldwork. However, when I came to reflect on my empirical findings, I did not find these understandings helpful, since it seemed to me that the relationship between the philosophy of care which workers in St

---

[4] Thomas S Kuhn (1962; 2nd edition 1969), *The Structure of Scientific Revolutions* [henceforth *SSR*]. Chicago: University of Chicago Press.

Z's "espoused" and their practices, or "theories-in-use,"[6] was not straightforward. I therefore returned to the literature and re-read Kuhn from the new perspective of my fieldwork findings. From here I discovered that his concept of the disciplinary matrix seemed to be relevant to my findings, providing a way of understanding the gap between espoused theories or beliefs and actual practices. In the second half of this chapter, therefore, I consider the concept of the disciplinary matrix in detail, and I end the chapter by outlining the implications of the disciplinary matrix for my study, in relation both to social constructivist studies and to the theory of total pain/care.

Thus, in relation to my findings, Kuhn's concept of the disciplinary matrix could seem to be the core of this chapter. However, I began my fieldwork with the sets of understandings which I outline in the first half of this chapter, so my fieldwork was shaped by these understandings, not by my understanding of the disciplinary matrix. As I have said, I am interested in the relation between theory and practice on several levels, including my own theory and practice, and aim to reflect on this throughout this thesis. In this chapter, therefore, I seek to outline my movement through various understandings of the social construction of knowledge, from those with which I began this study to those, particularly the concept of the disciplinary matrix, to which I moved through reflecting on my fieldwork.

HOW I CAME TO SCIENCE STUDIES

I am female, born into a firmly middle class family in the south of England, although with a varied ancestry, including European and Irish, as well as English. My father was a psychiatrist, and my mother a nurse, the sister of a gastroenterologist and daughter of a GP, who was himself the son and grandson of GPs. From a very early age I was saying

[5] Ludwik Fleck (1935; 1979, edited by Thaddeus J Trenn and Robert K Merton; translated by Fred Bradley and Thaddeus J Trenn), *Genesis and Development of a Scientific Fact* [henceforth *G&D*]. Chicago and London: University of Chicago Press.
[6] Chris Argyris and Donald A Schön (1974), *Theory in Practice*. San Francisco: Jossey-Bass.

that I was going to be a doctor when I grew up. This was unusual for a girl in the 1960s-70s, but less so in a family where medicine was established as an occupation. I was encouraged in my desire to become a doctor, and I duly took the appropriate A levels and (after a year off) went to a Scottish university to study medicine.

A medical family background is fairly common amongst medical students, but there is also a complex relationship between my motivation to study medicine and my mother being diagnosed with multiple sclerosis when she was in her late 20s with three pre-school daughters, of whom I was the middle one. I will explore this issue in a little more detail below, but here will simply comment that my mother's multiple sclerosis advanced relatively quickly, and she died halfway through my first year at medical school. In my third year I had an appendectomy (which was a miserable experience),[7] and my mother's father, to whom I was very close, and who was supporting me financially, had a series of strokes, which left him significantly disabled.

With hindsight, these events compounded my general unhappiness with medicine, which began early in my first year, and had several aspects. First, I found the work of a medical student tiring and stressful, in particular the focus on learning facts, the relevance of which was hard for me to see (with hindsight, this was to do with my discomfort with the underlying theory – see later discussion). Second, as I proceeded through the course, my contact with many of my non-medical friends decreased, owing to the intensive nature of studying medicine.[8] Third, the thought of the immediate future, the life of a junior doctor, was unappealing to me, it seemed to entail hard, tiring work, and to be a particular struggle for women, given the strongly male-dominated and male-centred nature of medicine at that time (there were few female consultants at that time – I met none – and there was a noticeable majority of male students in my year and those above and below it). The promise of a life of relative independence and financial

[7] See the psychiatrist Oliver Sacks' discussion of how his experience of hospital care changed his perception of medicine in *A Leg to Stand On* (1991). London: Picador.

security beyond the immediate future did not seem to me to be much compensation for all of this.

But also, and more profoundly and fundamentally, I did not believe in what allopathic medicine claimed to do or to be (although this was not something which I could have articulated at that time). I enjoyed some subjects, particularly gross anatomy, since I found the structure of the human body beautiful, and took great pleasure in exploring how muscles and tendons worked, how organs were arranged, and so on. However, I was more uncomfortable with other subjects, such as histology (microscopic anatomy), biochemistry and physiology. To me, the theories and explanations of these subjects seemed to have little to do with people's experiences of ill health. More widely, I was extremely uncomfortable with the closed, restricted focus on the physical aspects of disease, and general ignoring of the relationship between society and health. However, I was told that what was important for medicine was to understand and explain in physical terms how human bodies worked and why things went wrong with them.

Nevertheless, I perceived many contradictions in allopathic medical knowledge, in particular, in how medicine dealt, or failed to deal, with chronic illness and death, most obviously in connection with the last few years of my mother's life, which she spent in a long-stay institution. I was also uncomfortable with the lack of care towards health care professionals, both current and future (that is, members of the student body), and the associated unspoken taboo around doctors getting sick, which was tacitly equated with weakness, especially in relation to mental health. Of those few medical students I knew who questioned the status quo, and who were not only or mainly interested in the status and money associated with a medical career, most left the course. One committed suicide in our second year, but this was never openly discussed, and this silence was later repeated when other students had mental health problems.

---

[8] The timetable of medical students involved classes most of the time for most days of the week, which was very different from the schedule of social science or arts students, whose timetables, apart from a few fixed lectures and seminars, were fairly flexible.

As I have noted, at that time (the early 1980s), the first two ("pre-clinical") years of medical study predominantly involved absorbing and regurgitating scientific facts. There was minimal non-scientific input, we had a one-hour session per term on medical ethics and similar subjects, which most students treated as the soft option and time out from "real" work. However, as part of this, I did a project in my second year on the Black report into inequalities in health and their associations with poverty.[9] Following this, I increasingly began to ask what it meant to be a doctor in a situation where health is so closely bound up with people's social circumstances, especially poverty and poor housing, and yet all a doctor seemed to do was provide local and particular assistance with physical issues to individual patients, only to send people back into the same situation. That is, I began to ask what allopathic medicine was for.

However, if I tried to raise any such questions with lecturers and/or clinicians, I received responses such as: you can't ask these questions yet; you're not qualified; wait until you're a consultant, then you can ask these questions. These responses resonated with my discomfort over successive years of science at school, where teachers would introduce revisions of knowledge which had previously been presented as the "truth," but did not welcome questions about how "true" the "new" knowledge was. Again, as with science at school, I had no way of questioning this attitude, which seemed to be (and was presented as) how science/medicine "just was."

Despite my unhappiness and discomfort, I completed the two pre-clinical years, hoping and being told that clinical medicine would be better, but clinical medicine felt like more of the same, if not worse. One of the first clinics in which I was placed was a general medical clinic in a hospital in a very deprived and depressed part of the city. The consultant in charge of us was a very stereotypical "old school" consultant: he smoked his pipe as we went from ward to ward, and put it, still alight, in the pocket of his white

[9] Douglas Black (1982; edited by Peter Townsend and Nick Davidson), *Inequalities in Health: The Black Report*. Harmondsworth: Penguin. The findings of this report were repressed by the Thatcher government, so (unsurprisingly), the Acheson report sixteen years later (Donald Acheson (1998), *Inequalities in*

coat when we went into the wards, and he referred to patients by their diseases or organs: "here's the stomach" or "here's the hepatitis."

One patient I still very well remember was a 10-year old boy with multiple pulmonary abscesses from injecting heroin. He had made an extraordinary recovery, and was a "great case history," his lungs having completely cleared following treatment, which made the contrast between his "before and after" X-rays very striking. However, he was going to return to exactly the same situation in which he had been using heroin before he was admitted to hospital, and although, when asked whether he would take heroin again, he duly responded that he would not, this seemed extremely unlikely to me. This event reinforced my earlier discomfort with the context-free nature of my studies and my questioning of the purpose of medicine.

There were 200 medical students in my year, but we had not even one personal tutor between us, so there was no intermediary between the students and the Dean of the medical school. At the end of my third year, as my unhappiness continued, and, if anything, increased, I went to see the Dean to ask if it was possible for me to take a year off to think about whether I wanted to continue with the course. He told me that medicine needed to change, and (therefore) needed people like me to question and change it. However, he told me that taking a year out was not an option; I either stayed or I left... unless (bizarrely enough) I was pregnant and wanted time off to have the baby and get it settled.

Other than the latter extraordinary comment, the Dean's refusal to allow me a year off was perhaps in part related to the fact that he had a vested interest in me continuing, since medical schools had to pay a financial penalty if medical students left the course. Nevertheless, I believe that he was genuine in his comments about medicine needing to change, since subsequently medical education has significantly changed (although these changes have been generated largely in response to public disquiet with

---

Health: An Independent Inquiry into Inequalities in Health: A Report. London: Stationery Office) found a similar situation

the medical profession, rather than being internally generated). In 1993 the General Medical Council published "Tomorrow's Doctors"[10] which emphasised the interactional aspect of medicine, and suggestions for revising medical school curricula, including such things as a consideration of the social context of ill health and the formal teaching of communication skills.

However, in 1985 the Dean offered me no support with questioning and changing medicine, just left me to get on with challenging the medical establishment: a rather large task for someone in their early 20s, especially given the response I received when I did question underlying assumptions. Since I was already deeply unhappy and felt so unsupported, I felt unable to continue with the course, although I was aware of the value of having the degree and the status/authority of an allopathic medical doctor, and that it would be therefore be worthwhile completing the course, even if I never practised medicine. Nevertheless, I felt very isolated, and did not feel that I had the strength to continue with something with which I was already so unhappy for the sake of perhaps in the long-term contributing to changing it. This would have meant that I would have had to accept everything with which I had such difficulty, against the possibility of possibly in the future having some small influence in changing it, and the personal cost seemed disproportionate to the possible (abstract, impersonal) gain.

Of course, my experiences were with particular consultants, particular hospitals, and a particular medical school, and it is not necessarily valid to generalise from them to medicine more widely. I was aware of this at the time, and, partly because of this, I thought that my unhappiness solely related to my personal difficulties with the demands made on me as a medical student and my personal perception that medicine contained so many contradictions and false claims. I still think that these factors played a significant part in my decision, although I now see them as not solely relating to me personally, but relating to how allopathic medicine is constructed.

[10] For details see http://www.gmc-uk.org/med_ed/default.htm (The 1993 document was revised in 2002).

In addition, however, as I have said, with hindsight I can see that my unhappiness was also largely connected with my mother's death (and previous illness), and that I needed help with this. But, firstly, I did not realise that I needed any help (my mother had been ill for so long that in a lot of ways her death was a relief, although this, of course, complicated my feelings). The two years' delay between her death and my increasing unhappiness is a fairly common pattern, I now realise, for people in this situation (often termed "complicated grief"[11]). Secondly, even if I had realised that I needed emotional support, I did not know what kind of support or help was available, nor that it was possible to look for it. I had never heard of counselling, and it had certainly never been suggested to me or my siblings,[12] while, as I have noted, there was a very strong message in the faculty that doctors and medical students did not get ill, especially not mentally, but "coped," which meant denying that anything was wrong.

The upshot was that I entirely rejected academia (as I have already noted, I had no personal tutor, so no one to point me towards careers or academic advice), and went into non-academic activities, first working in a radical bookshop collective in Scotland, and then, in the late 1980s, teaching English in Spain. However, it gradually became clear to me that my lack of a degree certificate (although I had a transcript of my three years at medical school), might become problematic in the future, particularly since higher education in the UK was beginning to expand. In 1990, therefore, I decided to begin studying for a degree, and chose the subject in a purely strategic, instrumental way. Since I planned to return to Spain or to go to Latin America once I had completed my degree, I decided to study Spanish. In addition, during the 1980s, information technology (IT) (a technology which, when I was at school, barely existed outwith

---

[11] See Sheila Payne, Sandra Horn and Marilyn Relf (1999), *Loss and Bereavement.* Buckingham and Philadelphia: Open University Press: 76-7. It is important to recognise, however, that, as Payne et al. note, "complicated grief" has not been consistently defined, and that, as they also argue, models of grief have tended to be interpreted in a normative way, whereas perhaps they need to be more flexible.

[12] This might seem odd given that my father was a psychiatrist, but many psychiatrists in the '70s and '80s did not value counselling. In addition, there was a strong unspoken understanding within my family that we dealt with my mother's illness by *not* talking about it, which links to the wider medical message that to need or seek help was in some way to fail.

scientific institutions, and was thus taught minimally) had begun to grow in importance. Since I knew little about IT and could see that it would become increasingly important, I therefore began a BSc in IT, taking Spanish as a minor subject.

When I began my BSc, therefore, I had no intention of pursuing an academic path. However, as I proceeded through my studies I began to see similarities between IT and medicine. I felt that both were founded on unquestioned assumptions; neither questioned that they were self-evidently beneficial, and, in both, the role of both students and (in early stages) practitioners seemed to be to accept and learn the given facts contained in these bodies of knowledge, not to question their underlying assumptions, nor the functions or origins of their content. As I had earlier asked about medicine, I began to ask what IT was for.

As I have noted, when I gave up medicine, I thought that the problem was with me, that, given the way medicine was, I personally could not be a doctor. When, studying IT almost 10 years later, I began to feel the same kinds of things about IT as I had felt about medicine, I began to think about my personal experiences and feelings differently, and to realise that they did not only concern me as an individual, but had something to do with the construction of science, technology and (allopathic) medicine ("STM") more widely.

My search for an understanding of this led me to write a (rather confused) dissertation, trying to explore my sense that computers stemmed from and illustrated an impossible desire for perfection, and, simultaneously, to think about, and explore options for postgraduate study of, the history and philosophy of science. Via this route I came across the MSc in Science and Technology Studies, offered by the Science Studies Unit (SSU) at Edinburgh. My sense of revelation at – and the wonder and relief of – discovering that I was not the only person asking why STM is the way it is, is still vivid to me, and, when I was offered a place and funding to study for the MSc, I accepted it.

Whilst I was studying for my MSc, a family friend died of malignant melanoma, and towards the end of his life he received hospice care at home. This was the first I had

heard of hospices (when I began my medical training in October 1982 the modern hospice movement was only beginning to become established), and it sparked my interest, so I began volunteering at a hospice in Edinburgh. My dissertation for my MSc explored fertility specialists' perceptions of the needs of patients receiving fertility treatment, and I initially intended to develop this for a PhD study. However, while volunteering at the Edinburgh hospice I became increasingly interested in hospice practice and philosophy, in particular, the theory of total pain/care. In addition, I thought that I might find studying an attempt to change dominant allopathic medical practice more inspiring than doing a study of the gaps and omissions in such practice (so confirming my initial discomfort with the predominantly physical focus of allopathic medicine).[13] I therefore developed a new PhD proposal, to investigate the spiritual aspects of hospice care, and was offered a place and funding to study for this.

Thus, I am where I am now for various, intimately interwoven reasons. My experience of studying allopathic medicine was extremely uncomfortable, indeed painful, but I had no way of understanding this at the time. Social construction of knowledge provided a way in which I could think about my experiences. The starting point for my exploration of the field was SSK (the sociology of scientific knowledge) (the main focus of the SSU), although I also took other courses run by the SSU or by the Graduate School of the Social Sciences, through which I discovered other approaches to the social construction of knowledge. I will now move on to outline these initial understandings of this field with which I began this study.

I will begin by outlining Kuhn's theory of scientific revolutions, which was one of my starting points, and also the point to which I returned after completing my fieldwork. I will then move on to discuss SSK and then to consider the various debates

---

[13] The work I had done on my MSc dissertation seemed to me to indicate that many of the needs of people having fertility treatment were not addressed (owing, in particular, to the emphasis on providing them with a baby, with the assumption that having a baby would resolve all their problems, which was not necessarily the case, even aside from the fact that most fertility treatments are unsuccessful) (see also Jeanette Edwards and Sarah Franklin (1999, 2nd edition), *Technologies of Procreation: Kinship in the Age of Assisted Conception*. London: Routledge), and I felt that I might find continuing to study this too depressing.

amongst social constructivists, focusing in particular on the positions of feminist and/or postcolonial theorists of knowledge, who I call "engaged social constructivists," which framed my approach to my fieldwork.

KNOWLEDGE AS A SOCIAL/CULTURAL PRODUCT

The "strong programme" (SP) of the sociology of scientific knowledge (SSK), developed in the so-called "Edinburgh school," drawing to a significant extent on the work of Thomas Kuhn,[14] although Kuhn was not the first theorist to suggest that knowledge was a social product, nor is SSK/the SP the only approach to studying the production of knowledge. Ludwik Fleck addressed similar questions several decades prior to Kuhn,[15] and challenges to the orthodox understanding of how scientific knowledge is produced have also come from other directions and other fields than the history and philosophy of science.[16] Some of these other challenges are centuries old; for example, Soheir Morsy cites the recognition of the 14th century North African scholar Abdul Rahman Muhammad Ibn Khaldun that knowledge was dependent on social, economic and political conditions.[17]

In *Structure of Scientific Revolutions*, Thomas Kuhn developed his theory of "scientific revolutions," that is, of how new scientific theories come to replace old ones. Kuhn argued that the production of scientific knowledge proceeds through phases of "normal science" which are periodically disrupted by, and alternate with, "scientific revolutions." Kuhn claimed that a "scientific community" produces what he called "normal science" within, and in interaction with, the framework of its set of beliefs, that is, the community's set of understandings of what the world is like. This set of

---

[14] Kuhn, op. cit. note 4.
[15] Fleck, op. cit. note 5.
[16] The orthodoxy which Kuhn/SSK questioned.
[17] Soheir Morsy (1996), 'Political economy in medical anthropology,' pp. 21-40 in Sargent CF and TM Johnson (eds.), *Medical Anthropology: Contemporary Theory and Method.* Westport, CT and London: Praeger: 21. Note that this insight predates even the birth and growth of Western science/natural philosophy.

understandings includes the scientific community's sets of answers to questions about the fundamental entities of the universe and how they interact – which answers both specify which entities the community believes exist, and also (indirectly) imply those entities which it believes do not exist. Kuhn argued further that, because the scientific community is unable to produce scientific knowledge independently of these beliefs, and because those beliefs – the basic commitments of the scientific community – always contain an arbitrary element, normal science repeatedly goes astray and fails to work as expected.[18]

Kuhn claimed that normal science occurs during periods of time when the scientific community concentrates on developing those theories on which its members agree. At these times the community as a whole does not question its theories, but rather uses them as a basis for the production of new knowledge, seeking to elaborate and confirm accepted theories via empirical findings. Kuhn argued that anomalies between theory and practice always exist and scientists usually find ways to explain these anomalies within the terms of the existing theory. However, at some times some scientists perceive that anomalies present insurmountable difficulties for an existing theory, judging that the existing theory does not adequately explain the anomalies. These scientists challenge existing theories on this basis and produce new theories, which they take as more adequate. Other scientists resist these new theories, and this may result in controversies, debates and disagreements between those who adhere to the existing theory and those who favour the new one.

The outcome of these negotiations may be that the scientific community rejects the new theory, but, if a significant number of scientists are converted, a "scientific revolution" occurs, whereby the community accepts the new theory, substituting it for the theory which they previously accepted. Once the new theory is established, normal

[18] Kuhn argued that observation and experience are insufficient to account entirely for the beliefs of a given scientific community, since the community's beliefs always have an arbitrary element, which is personally and historically formed, although observation and experience act to *limit* (constrain) the beliefs

science begins again. However, this does not simply mean that scientists add the new theory to prior scientific practice, since new facts or theories are interwoven and inseparable, and (therefore) affect the whole network of scientific understandings and concepts.[19] Thus, the scientific community's acceptance of the new theory alters the network of scientific knowledge and scientific knowledge production, and so normal science begins again within a network of scientific knowledge, knowers and knowledge producers which has been altered, whether slightly or significantly. Scientists gradually begin to assimilate the new theory; reconstructing and re-evaluating existing knowledge from the new perspective, and this is an extended process, not a single, isolated event.

Kuhn argued that perception and sensation are learnt and participatory, and that scientists learn about science by being shown the similarity sets which apply to their particular field, using exemplars to develop their perceptions both of similarities between situations, and also of which situations do and do not occur. That is, he argued, learning about science and becoming a scientist are interwoven social processes,[20] the outcome of which is tacit knowledge, where the learnt, constructed, participatory character of knowledge becomes invisible.

Thus, Kuhn asserted that people *learn* how to perceive sensations, that is, that group members learn to perceive the same things when confronted by the same stimuli, through encountering examples of situations which their predecessors in the group have already learned to perceive as like each other.[21] Kuhn claimed that this recognition

---

of a given scientific community, the community's beliefs are always *underdetermined* by observation and experience (Kuhn, op. cit., note 4: 4-7).

[19] Kuhn, op. cit., note 4: 6-7.

[20] See also Jean Lave and Etienne Wenger (1991), *Situated Learning: Legitimate Peripheral Participation.* Cambridge: Cambridge University Press.

[21] Kuhn argued that since very different stimuli can result in the same sensation, or the same stimuli can result in different sensations, what people perceive are sensations rather than stimuli, and these can differ between individuals and groups. Individuals who belong to the same groups, with shared experiences, education, and so on, can communicate, and this suggests that their sensations are similar. But nothing can be said about the sensations of other groups (Kuhn, op. cit., note 4: 193).

becomes unintended and involuntary,[22] but pointed out that, although perception is not (therefore) an interpretive process, people are not able to have any perceptions whatsoever. He argued that people have selected certain ways of perceiving because of their proven success over time, and so the stimulus-to-sensation route does embody people's experience and knowledge of nature, but the knowledge embedded in this route remains tacit.[23]

I suggest that a consequence of this is that the perceiver perceives their perception as inevitable/self-evident, obviously true, and takes it for granted as "how things are." Similarly, the theory which has been constructed in relation to the perception also seems inevitable and self-evident. As Fleck stated:

> Whatever is known has always seemed systematic, proven, applicable, and evident to the knower. Every alien system of knowledge has likewise seemed contradictory, unproven, inapplicable, fanciful or mystical.[24]

---

[22] Kuhn argued that people do not apply rules and criteria to perception (which implies that they/we have alternative ways of perceiving things), but rather that people perceive sensations in the way in which they have learnt to perceive them (Kuhn, op. cit., note 4: 194-5). Thus, the nature and amount of a person's prior experience and training shapes perception, and also shapes what perception leaves for interpretation to complete. People may engage in interpretation and so, *after* they have perceived something, they may employ rules, but Kuhn argued that we can only experiment with other ways of perceiving *after* we have perceived something. That is, perception, while learnt, and not inevitable, is not itself an interpretive process. Similarly, Ludwik Fleck claimed that we are unaware of how we contribute to what we call "reality," taking for granted the basic fact that a normal person has two eyes, and being unconscious of how we participate in perception. Instead, Fleck argued, we feel a complete passivity in the face of something that is independent of and external to us; a power which we call "existence" or "reality," which we no longer examine critically but accept mechanically or habitually, and he drew a parallel with how someone participating in a mass movement is caught up in the excitement of it and is thus unaware of their own contribution to it (Fleck, op. cit., note 5: xxviii).

[23] Because perception is non-interpretive, we have no direct access to what we know; we can only know of stimuli through theoretical conjecture (Kuhn, op. cit., note 4: 196-8).

[24] Fleck, op. cit., note 5: 22. Fleck argued further that we are inseparably linked to the past, including all its errors, since the past survives in language and in institutions, and (including) in how problems, and concepts, are presented. As a result, he claimed, most, if not all, of the content of science is conditioned by its history, so that problems and concepts are not spontaneously created but are determined by their ancestors, which Fleck termed "proto-ideas." (Fleck, op. cit., note 5: 20). In *G&D*, Fleck tracked the development of the allopathic medical fact (or belief) that the Wassermann reaction is related to syphilis. He argued that the idea of syphilitic changes in the blood existed centuries before scientific proof was available, and that the medical fact was an idea which emerged from a chaotic mixture of ideas, becoming more and more substantial and precise over time, as evidence for it was adduced from various points of view, until it was finally scientifically embodied in the Wassermann reaction. Fleck concluded that the Wassermann reaction constitutes the modern, scientific expression of an earlier proto-idea which

However, despite this perception of current knowledge as proven, and self-evident, Fleck argued, many scientific positions developed from ideas which, although they cannot be considered to be errors, were not based on the same kinds of proof considered valid today.[25] So, for example, Fleck claimed that '[t]he formation of the concept "disease entity" involves synthesis [of previous and new ideas] as well as analysis,' and that 'the current concept does not constitute the logically or essentially only possible solution.'[26] Thus, he argued, current research techniques were the result of their history, and so historical and comparative epistemology were important.[27]

Kuhn's ideas parallel those of Fleck,[28] and the latter's concept of "thought collective,"[29] but Fleck claimed that the study of recent medical facts was important,

---

contributed to the concept of syphilis (ibid.: 23), and argued that the Wassermann reaction was accepted only because it proved to be useful (ibid.: xiv; 21).

[25] Fleck, op. cit., note 5: 24-5.

[26] Ibid.: 22. Fleck stated that the argument of people who believe that science is a process of accumulation of truth, that is, that scientists have accepted the "right" ideas and rejected the "wrong" ones from the large number of somewhat hazy ideas which have emerged throughout history, does not explain why there are so many possible correct representations of unknown objects. He argued that the categories of truth and falsehood could not be applied to proto-ideas, which, although they do not correspond to modern scientific thought, cannot be judged true or false by any absolute criterion of judgment. Facts, he claimed, develop step by step from hazy "proto-ideas" which we cannot judge as either right or wrong, because they belong to their chronological context, and 'correspond to a different thought collective and a different thought style,' which took them to be true. So, for example, Fleck argued that the concept "syphilis" means something entirely different today from what it meant previously, and that the value of this proto-idea resides in its contribution to the development of what is currently taken to be a fact (ibid.: 25).

[27] Fleck (ibid.: xxviii) argued that, since we are so accustomed to long-established facts, both theoretically and in practice, it is difficult to conduct an unbiased epistemological investigation into them; it is easier to neutrally investigate more recent facts. But he asserted that epistemologists often committed a fundamental error by almost exclusively taking well-established facts of everyday life, or of classical physics, as the only ones that were reliable and worthy of investigation.

[28] Kuhn did not directly draw on Ludwik Fleck, but he cited Fleck (Fleck (1935), *Entstehung und Entwicklung einer wissenshaftlichen Tatsache*) in *SSR*, and has stated that, although he was uncertain what precisely he took from Fleck's work when he wrote *SSR*, he was reassured by its existence, first, because Fleck was one of the few people who perceived the same things in the history of science as Kuhn, and, second, because Fleck's work enabled Kuhn to realise that the problems that concerned him had a fundamental sociological dimension (Kuhn, foreword to Fleck, op. cit., note 5: viii).

[29] Trenn et al discuss translation between languages in relation to *Denkstil*, "thought style," and *Denkkollektiv*, "thought collective," arguing that Fleck explicitly meant "collective" (with its attendant sociological meaning), *not* "community," of thought, nor "school of thought," which latter term, they point out, is ambiguous, since it conveys aspects of both *Denkstil* and *Denkkollektiv*, which, although inseparable from one another, are distinct concepts (Trenn et al, preface to Fleck, op. cit., note 5: xvi).

applicable, and rewarding historically and phenomenologically,[30] and, in contrast to Kuhn's later focus on natural science, particularly physics, he argued that:

> medical science, as an important facet of the development of modern civilization, can and should complement natural science in approaching rational epistemology and historiography of science.[31]

Thus, Fleck argued for the investigation of knowledge from both medical and natural science, and I will argue later that Kuhn's analysis of science can also be applied to allopathic medicine.

Incommensurability, translation and conversion

Kuhn argued that scientists do not explicitly learn similarity relations, and are usually unaware of how they themselves contribute to their perceptions of the situations which they encounter. One central aspect of any scientific revolution (change in scientific theory) is that for some scientists some of the similarity relations change, and they may therefore find that their descriptions and generalisations with regard to the same stimuli are different from those of other scientists who still adhere to the existing theory. However, since scientists have learned the language in which they talk about these stimuli in use, that is, by direct application to exemplars, they have no language *external* to their theories in which to talk about their differences.[32]

Thus, Kuhn argued, although people use the same language in debates over scientific theories, they perceive the situations differently.[33] This suggests that they must be using some identical terms to mean different things, which implies that their definitions of those terms must have changed. He argued that these differences do not mean that people cannot communicate at all, but they do mean that debates over theory

---

[30] Fleck, op. cit., note 5: xxviii.
[31] Ibid.: 168.
[32] Since part of the difference between their theories is prior to the application of the languages in which it is reflected (Kuhn, op. cit., note 4: 201).
[33] As I will highlight later, following my fieldwork I began to see this as an important point in relation to the spiritual aspects of care.

differ from debates over proof. In debates over proof for existing theories, premises are established from the start, but debates over theory-choice concern *the premises themselves*. However, people can still persuade others to favour one theory over another on the basis of reasons such as accuracy, simplicity, fruitfulness, scope, and so on.[34]

Kuhn argued that, because of these differences in language use, a new theory is incommensurable with its predecessor, that is, a scientist is unable to simultaneously hold both the previous and the new theory. A scientist may still find the old way of perceiving situations comprehensible (s/he is able to adopt the old perspective, having once held it), but s/he cannot sustain both the old and the new perspective.[35]

Similarly, Fleck commented on the 'difficulties, possibilities and limitations of transmitting ideas between and participating in more than one "thought collective,"[36] and argued that:

---

[34] See my discussion of values later in this chapter.

[35] Nevertheless, Kuhn held that people who disagree are still able to find out a great deal about how they differ, by becoming 'translators', that is, by attempting to discover the areas and the linguistic terms in which lie the difference between them and others, and trying to identify the differences between their own response to a particular stimulus and that of someone who holds to a different theory. Kuhn argued that, if such 'translators' refrain from explaining anomalies as madness or error, they become able to predict each other's behaviour (in the same way as a historian of science does when considering past theories). (Kuhn, op. cit., note 4). See also Peter Winch's consideration of describing rather than explaining or judging beliefs (Peter Winch (1990, 2nd edition), *The Idea of a Social Science, and its Relation to Philosophy.* London: Routledge and Kegan Paul).

[36] In his foreword to Trenn et al, Kuhn notes that on re-reading Fleck he was impressed by this, although he also argues that Fleck's notion of a thought collective seems to function as an analogy with an individual mind, and claims that Fleck's frequent use of terms borrowed from discourse about individuals to discuss thought collectives can imply that in the absence of social pressures people would not hold illusory beliefs. Yet, Kuhn argues, Fleck uses language elsewhere which suggests that the force of a thought collective is an internal compulsion or constraint, independent of external pressures. That is, Kuhn claims that Fleck's argument suggests that the communication of thoughts within a collective, whatever their content or logical justification, leads to the corroboration of the thought structure (*Denkgebilde*), and that this implies that the effects of participation in a thought collective somehow override or precede any thought at all. Kuhn argues that this suggests that for Fleck '[t]he authority of a thought collective is more nearly logical than social, yet it exists for the individual only by virtue of his induction into a group.' Kuhn states that Fleck occasionally attempts to develop this problematic position by distinguishing between passive and active elements of knowledge, again borrowing from individual psychology, but that this is unsatisfactory. Kuhn says that he prefers the epistemic distinction between knowledge and belief, but points out that such difficulties have been central to philosophy since Wittgenstein, and remain unsolved (Kuhn, foreword to Trenn et al, op. cit., note 5: x-xi).

> [t]he conceptual creations of science, like other works of the mind, become accepted as fact through a complex process of social consolidation. These thought products, and the thought style under which they arise, are never finalized but can undergo transformation through intra- or intercollective interaction... marginal men participating in diverse thought collectives can create something new from the conflict. The older way of looking at things *may become incomprehensible* under the new thought style, and the process of transformation from one to the other *may be a rapid gestalt switch or a slow process of differentiation* like that between variation and species.[37] (My emphases).

Kuhn claimed that, in part because of the incommensurability between a new theory and its predecessor, a kind of conversion experience (like Fleck's "gestalt switch") is at the heart of the process of scientific revolutions. He argued further that, while good reasons for choice between theories provide motives and a climate for conversion, and while translation between new and existing responses (theories, or explanations) to stimuli (such as the results of scientific experiments) may provide points of entry when scientists choose a new theory over an existing one, good reasons and translation are not enough for conversion; that is, they are necessary but insufficient conditions.[38] Kuhn argued that to make a theory one's own, 'one must go native,' that is, begin to think and work in the other language. But, he claimed, an individual cannot *choose* to make that transition; s/he may be fully persuaded by the new theory but unable to internalise it.

Thus, for Kuhn, a person's conversion from an existing theory to a new one means that they move – via a process of internalisation ("going native") – from theory (intellectual conviction) to practice (action). This movement was something which, before I began my fieldwork, seemed to me to underpin the growth of the modern

---

[37] Trenn et al, preface to Fleck, op. cit., note 5: xiii. Nevertheless, Trenn et al. claim that Fleck's ideas do not map onto Kuhn's sharp distinction between normal and revolutionary science, and nor, therefore, the 'controversial concept of revolutions' (ibid.: xiv). However, I think that Fleck's claim that the old way of looking at things may become incomprehensible, and that change from the old to the new way of looking may be a rapid gestalt switch equates to Kuhn's idea of scientific revolution (that is, scientists' complete rejection of an old theory and replacement of it by a new one), even though complete theory change may be rare, and the gradual transformation of theory to which Fleck referred may be more common.

[38] Kuhn, op. cit., note 4: 204. Again, these are points which became important to me when reflecting on my fieldwork.

hospice movement – people were converted to the theory of total pain/care and implemented it in practice. However, as, following my fieldwork, I reflected on my findings and on the writing of this thesis, this movement became even more significant for me, and I returned to Kuhn to consider it further. I will outline my further reflections when I discuss Kuhn's concept of the disciplinary matrix later in this chapter.

In the following sections, however, I will continue to outline the understanding of the theory of the social construction of knowledge which I took with me to the field, which included only the understanding of Kuhn which I have described so far.

The Sociology of Scientific Knowledge

In the 1970s practitioners of the new field of the sociology of scientific knowledge (SSK) picked up on Kuhn's point that '[s]cientific knowledge, like language, is intrinsically the common property of a group or else nothing at all.'[39] They built on Kuhn's work to argue that knowledge is a social process, embedded in the doing and practice of science, and thus that knowledge of nature (science) is part of culture and therefore a facet of collective life.[40]

David Bloor, a founder of the "strong programme" (SP) of SSK,[41] argues that Pierre Duhem's claim that scientists have to test, accept or reject any hypothesis within a network of associated assumptions and hypotheses (which includes an infinite number of auxiliary hypotheses beyond those beliefs which people explicitly hold)[42] raises the question of why people choose to accept one set of arguments rather than another, and

---

[39] Kuhn, op. cit., note 4: 210.
[40] David Bloor (forthcoming), 'The sociology of scientific knowledge,' pp. 1– 48 in I Niiniluoto et al (eds.), *Handbook of Epistemology*, Dordrecht: Kluwer Press: 1.
[41] A key text is David Bloor (1991; 2nd edition), *Knowledge and Social Imagery*. Chicago: University of Chicago Press.
[42] Bloor, op. cit., note 40: 2, citing Pierre Duhem (1906/54), *The Aim and Structure of Physical Theory*. Princeton: Princeton University Press. See also Willard O Quine (1960), *Word and Object*. Cambridge, MA: MIT Press; (1963), *From a Logical Point of View: 9 Logico-Philosophical Essays*. New York: Harper and Row; and (1995), *From Stimulus to Science*. Cambridge, MA and London: Harvard University Press.

on what bases they do so. Building on Kuhn's "scientific community,"[43] Bloor points out that scientists never operate alone, but within networks of colleagues, either directly or through knowledge of their colleagues' work. These contexts and networks shape scientists' personal judgements of credibility, why they choose to invoke particular authorities for their decisions, opinions and theories.[44] Bloor argues that '[w]e do not know the world in spite of or without society; we know it collectively, by means of society.'[45] It is scientists' *shared* understanding and *shared* conception of what they are doing which gives their findings the status of evidence, since it is only such a *shared* conception that enables them to perceive findings as supporting or contradicting one another.[46]

Bloor argues that what a group takes as evidence is itself a social category, since it cannot be defined without reference to a conventional component,[47] and a group

---

[43] Which, as noted, also echoes Ludwik Fleck's "thought collective."

[44] Bloor, op. cit., note 40: 30. That is, despite the myths of the lone scientific genius, such as that associated with Einstein, no scientist truly works alone.

[45] Bloor, op. cit., note 40: 10. Scientific knowledge is social, Bloor argues; that is, it is embodied in a structure of social conventions and institutions, such that society is the channel by which scientific facts (accounts of the world) are produced. That is, scientists respond to nature *through* society; society mediates scientists' response to nature. Thus, social structure, conventions and institutions are not obstacles, sources of contamination or distraction, which get in the way of the production of scientific knowledge, but are precisely the opposite: they *enable* scientists to produce knowledge. Yet, as Bloor points out, to say that knowledge *about* reality is a social/cultural product says nothing about reality itself, and he differentiates between fact as a state of affairs, "how things are," and fact as an *account* of how things are. Nevertheless, social constructivism is frequently interpreted as claiming that society *creates* nature (rather than *theories about* nature), and is then attacked on that basis, even by people who count themselves sociologists of knowledge. See, for example, the "science wars" and disagreements within the field of social construction itself, which I discuss later in this chapter. Not all scientists criticise social constructivism, however; a friend of mine, a laboratory microbiologist, says that a theory is just something that hasn't been proved wrong yet, and Hilary Rose argues that few contemporary scientists believe that they are making absolute truth claims; they recognise that scientific knowledge is provisional, hedged around with conditions... except when they are seeking more resources, 'when the ideology of science is wheeled out to provide the rhetoric of certainty' (Hilary Rose (1994), *Love, Power and Knowledge: Towards a Feminist Transformation of the Sciences*. Cambridge and Oxford: Polity Press: 25). This use of the ideology of science is precisely the issue, of course, since the ideology is used as a way of bolstering science and attacking those who point to the contradictions in practice, even though the ideology is not borne out in practice.

[46] Bloor, op. cit., note 40: 11-3. That is, the conventional underpinning of an inference does not cause it to be wrong, but is the basis on which a scientist judges it as right or wrong.

[47] Bloor, op. cit., note 40: 34.

identifies areas of interest, valid evidence, and relevant authorities on the basis of its own criteria. It does not do this randomly or haphazardly, but nor does it make these choices by any absolute methodological principles. The group's choice is systematic, but it is made within the group's sets of principles, which are relative to the group's situation.[48] That is, people take a particular belief to be true because it fits into a network of their other beliefs about nature and science, which are themselves a blend of observations and prior beliefs and theories. Bloor asserts that different groups have different ways of understanding and responding to the world, and (because) they have different kinds of conventions and institutions.[49]

Bloor states that treating things as identical is a theoretical claim, which a group of concept users (such as scientists) sustains[50] (although this is not necessarily done consciously/explicitly), and argues that a group's move from past applications to new applications of a concept is contingent; it occurs in a changing interpretive climate, where negotiations and agreements occur. Concepts act as precedents for future applications; that is, concept application is normative and consensual: standards of right and wrong derive from people's agreement, as evidenced in use, and the credibility of a theory or belief only makes sense within a social context.

That is, Bloor claims, what is correct is what a group of users agrees is correct; without such normativity there would be no meaning. Drawing on Wittgenstein's claim that meaning is use, Bloor argues that: '[m]eaning itself is [...] a sociological

---

[48] Bloor, op. cit., note 40: 31.
[49] Bloor, op. cit., note 40: 21-2.
[50] Bloor, op. cit., note 40: 8. Bloor points out that objects underdetermine the conclusions we draw about them; since the same object can prompt different beliefs or accounts of it, the object alone is insufficient to explain those differences. That is, he argues, although objects have causal powers for belief formation, objects *alone* are insufficient for how people construct beliefs about them, while experimental objects are themselves already human creations. Bloor states that an observer's knowledge is thus made up of both the contribution of an object to the observer's cognitive experience, and also the contribution of the observer's cognitive/perceptual system to that experience; it is not a straightforward (empirical) question to determine the proportion of these two ingredients that make up knowledge. This links to Kuhn's discussion of perception as learnt, and to Kuhn's claims concerning how scientists learn to group things as similar by using exemplars (paradigms) as foundations for similarity sets (see my discussion of this later in this chapter).

phenomenon,'[51] constructed in social interaction, and unintelligible otherwise. That is, meaning claims are normative and prescriptive: as Alessandra Tanesini also argues, meaning is not simply use, but *correct* use (as agreed by a group).[52]

Thus, SSK holds that (scientific) theories and the application of concepts and theories are normative and conventional, that is, that they are social institutions. So, knowledge and credibility are also normative and conventional, and for SSK, credibility and belief are to be explained in terms of local and contingent causes outwith the content of any particular theory. The SP investigates scientific controversies using the principle of "methodological symmetry," which, rather than seeking to evaluate theories for their truth or falsity, asks why one group believes one theory and another group a different one, and explains this in relation to the social interests of the scientists involved.[53]

That is, "methodological symmetry" means that the investigator does not evaluate the truth or falsehood of a particular belief; s/he does not use evaluation of truth or falsity for explanation, but treats this as part of what is to be explained. Bloor argues that this is a scientific approach to studying the production of knowledge, since the analyst suspends her/his personal beliefs to examine how belief is produced, and so the SP is a version of the scientific attitude: a symmetrical distribution of curiosity.[54] Thus, rather than assuming that scientific knowledge is *per se* true, rather than judging scientific theories as correct or incorrect, the SP investigates how and why *scientists* come to make those judgments. So, the SP seeks to describe the circumstances in which

---

[51] Bloor, op. cit., note 40: 9.

[52] Alessandra Tanesini (1996), 'Whose language?' pp. 353-66 in Garry and Pearsall (eds.), *Women, Knowledge and Reality: Explorations in Feminist Philosophy*, 2nd edition. New York and London: Routledge.

[53] SSK holds that empirical evidence alone does not determine whether scientists challenge an accepted theory or not; social factors are involved, both in whether controversies develop or not, and also in relation to how they are resolved. SSK argues that controversies are points at which differing perceptions between scientists are most apparent, and highlighted in their disagreements, as opposed to normal science where scientists are more or less united in their practice, and so differences between them are far less evident. Controversies, therefore, are points at which the social factors involved in theory change are most evident.

[54] Bloor, op. cit., note 40: 20.

groups of scientists come to hold their beliefs, but not to criticise or judge the truth or falsity of the beliefs which they hold.

DEBATES BETWEEN PROPONENTS OF THE SOCIAL SHAPING OF KNOWLEDGE

As I have noted, SSK is not the only approach to doing science studies; there are multiple approaches (which are not necessarily discrete, but at times overlap and link with one another), and at times vigorous debates and disagreements between the various proponents of the various approaches. These debates often present themselves as contradicting Kuhn and/or SSK, although, as I will argue, I think that this is seldom the case. In this section of the chapter I will now move to discuss those aspects of these debates which I took as relevant to my study when I began it, in particular discussions concerning the "disunity of science;" the field of "science as practice;" debates concerning explanation or description; and arguments from "engaged social constructivists" (mostly feminist and postcolonial theorists of knowledge).

Some theorists argue that there is no single "science," that science is not a monolithic entity, but a mass of disparate fields and approaches. So, for example, Peter Galison[55] states that science is not a unitary enterprise and that there are marked disunities in how science is practised in different places and by different groups of people.[56] Thus, he argues, scientific knowledge is local, and the world of science is

[55] Peter Galison (1987), *How Experiments End.* Chicago and London: University of Chicago Press. Also see Peter Galison and David Stump (eds.) (1996), *The Disunity of Science: Boundaries, Contexts and Power.* Stanford: Stanford University Press.

[56] Peter Galison (1996a), 'Introduction: the context of disunity,' pp. 1-33 in Galison and Stump (eds.) *The Disunity of Science*: 9. See also Ian Hacking, who argues that sciences are disunified not only because of the proliferation of specialisations, but also because different techniques produce different phenomena, which different theories explain. Hacking claims that laboratory sciences mature by evolving together with their instruments and theories, and that, while new data may make an old theory invalid, they still hold for their own domain (Hacking (1992), 'The self-vindication of the laboratory sciences,' pp. 29-64 in Pickering, A (ed.), *Science as Practice and Culture.* Chicago and London: University of Chicago Press: 56-7).

'more like a quilt than a pyramid;'[57] a disunified, heterogeneous assembly of a variety of languages, practices, aims and forms of argumentation, and, Galison claims, this disunity is precisely what gives the scientific enterprise its strength and coherence.[58]

That is, for Galison, science is not a collection of disjoint, internally coherent frameworks, but, instead, scientific knowledge is like a stone wall or rope, made up of disparate parts, and the strength of scientific knowledge, and so of science, results from the intercalation of these not precisely matched components.[59] Galison argues that, while scientific cultures differ, they experience continuity by working out 'partial, local, and specific linkages' between themselves. Galison claims that various subcultures of science develop local "trading zones" in which they co-ordinate their practices, and that people from different disciplines communicate when working together by developing an intermediate, pidgin language.[60] While each discipline differs on the best possible definitions of terms, these scientists produce good enough definitions of terms to enable them to work together.[61] Thus Galison argues that, in the development of the "Monte

---

[57] Galison, op. cit., note 56: 3.

[58] Galison, op. cit., note 56: 13. Galison argues that Kuhn's use of the Gestalt metaphor – whereby in the duck-rabbit line drawing someone sees either a duck or a rabbit, but never both, which Kuhn used in relation to scientific theories to illustrate that people accept either an established theory or its alternative, but not both – evokes 'a picture of science in which change comes slowly against a stabilizing theoretical framework that eventually collapses all in a piece,' but that this 'monolithic' picture is problematic.

[59] Galison, op. cit., note 56: 15. Similarly, Richard Creath ((1996), 'The unity of science: Carnap, Neurah and beyond,' pp. 158-69 in Galison and Stump (eds.), *The Disunity of Science*: 167) points out that the US pragmatist CS Peirce also used a cable/rope metaphor to defend his theory of coherentism, arguing that strength is produced from the overlapping between individually small, not especially strong components. Creath argues that the metaphor is neither anti-unity nor anti-order, but suggests that some orders are better than others.

[60] In her work on cancer research, Joan Fujimura ((1992), 'Crafting science: standardized packages, boundary objects, and "translation",' pp. 168-211 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press) uses a similar concept of "standardized packages" (which in turn are similar to the "boundary objects" of Susan Leigh Star ((1991), 'Power, technology and the phenomenology of conventions: on being allergic to onions,' pp 26-56 in Law, J (ed.), *Power, Technology and the Modern World*. Oxford: Blackwell) which Fujimura references in the title of her paper). Fujimura explores how people from a wide variety of social worlds came together in what she calls "the molecular biology bandwagon," using particular cultural elements in order to establish links between their different social worlds.

[61] Galison, op. cit., note 56: 14-15.

Carlos,"[62] scientists from different specialties formed a "trading zone" between themselves in which they managed to work together using a pidgin language, which gradually built into a creole. A self-supporting scientific subculture emerged from this process, and Galison claims that in this way, within this new subculture, a new "paradigm" emerged.[63]

Galison takes his position as contradicting Kuhn and the positions of SSK/the SP, but it seems to me that what Galison contradicts is in fact his own understanding of Kuhn; I see his position as amplifying rather than contradicting that of Kuhn. Galison states that science does not split into separate blocks and periods where experiment and theory were fused, and which cannot communicate with other blocks. He takes his discussion of the Monte Carlos as illustrating that this is not the case, and so as contradicting his understanding that Kuhn argued that translation between "paradigms" was impossible. My understanding, however, is that Kuhn claimed that established theories are incommensurable with their successor theories, that is, that people cannot simultaneously adhere to both existing theories and their potential successors. This does not (necessarily) mean that different scientific disciplines are incommensurable with one another. Further, Kuhn argued that an individual could not simultaneously hold incommensurable theories, not that people could not communicate with one another if they held incommensurable theories. Indeed, Kuhn discussed translation as enabling communication between such people.[64]

Another approach to science studies began in the 1980s, when other theorists began to turn their attention to science as (and in) practice. Andrew Pickering argues that this was a key advance in science studies, since, he claims, understanding scientific practice is important both in its own right and also for developing critical, policy-

---

[62] Computer-generated realities, first developed in the 1940s and '50s.

[63] Peter Galison (1996b) 'Computer simulations and the trading zone,' pp. 118-57 in Peter Galison and David Stump (eds.) (1996), *The Disunity of Science: Boundaries, Contexts and Power.* Stanford: Stanford University Press: 152-3.

oriented perspectives on science.[65] Studies of science as practice focus on how scientists do science as opposed to how they construct scientific theories, and Pickering argues that scientific practice is not simply about scientists extending a conceptual network (theory or set of theories) to fit new circumstances,[66] but involves scientists making associations between different elements in a patchy culture.[67]

Doing this requires scientists to struggle with resistances or recalcitrances, which can arise in various areas of practice: conceptual, material, or sociotechnical. This, Pickering argues, means that the closures which scientists achieve are not definitive, and the social is necessary to understand which of the possible closures a community finally selects. Pickering and Stephanides say that scientific practice has some enduring regularity, but resistance and achieving association also involve 'choice, chance, and contingency.' They argue that practice is not the straightforward implementation of theory; theory, practice and interests all influence one another.

---

[64] Thus, the people whom Galison discusses in relation to the Monte Carlos developed a pidgin precisely because their theories were not identical, but, rather than challenging and seeking to replace existing theories, they instead created a new theory in parallel to existing ones.

[65] Andrew Pickering (1992), 'From science as knowledge to science as practice,' pp. 1-26 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press. Pickering claims too that studies of scientific practice also have implications for disciplinarity since they tend to undermine traditional disciplinary boundaries, because concepts from single disciplines are insufficient for such studies, and argues further that such studies challenge conceptualisations which are central to modern thought, such as distinctions between subject and object, nature and society (ibid.: 6-7).

[66] Pickering contrasts his approach to that of SSK, stating that proponents of SSK conceptualise scientific knowledge as relative to a particular culture and to the interests of scientific actors, and have tended to focus on the products of scientific practice, especially the conceptual product: knowledge, rather than practice itself. He claims that proponents of SSK then (therefore) conceive of practice as scientific actors' extension of an existing conceptual network to fit new circumstances, and that proponents of SSK assert that scientific actors achieve closure and consensus by assessing how new conceptual nets fit with their interests. Pickering claims that this image of practice and culture is thin, idealised and reductive, foregrounding certain features of science at the expense of others, and that it does not offer the necessary conceptual apparatus for the richness and complexity of the doing of science. He argues that proponents of SSK treat the material dimension of science as simply more documentation of the SSK thesis of social relativity, yet, he claims, empirical studies of science often go beyond and challenge the SSK analysis (Pickering, op. cit., note 65: 5-6).

[67] Andrew Pickering and Adam Stephanides (1992), 'Constructing quaternions: on the analysis of conceptual practice,' pp. 139-67 in Pickering A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Pickering claims that studying science as practice provides different insights than those obtained by studying scientists' production of scientific theories, and I suggest that this is so because studies of "science as practice" focus on current, ongoing activities, and their associated messiness, that is, on what Kuhn termed "normal science," rather than on controversies and changes in scientific theories (Kuhn's "scientific revolutions"). In explorations of current practices an investigator will not see scientific revolutions, since these can only be identified retrospectively. Thus, different factors are relevant when studying current scientific practice than are relevant for the study of how scientists challenge existing, established scientific theories and come to agree to change them. The focus of these studies on current practice also seemed to me, as I began this study, to be more relevant to what I was trying to do than studies of theory change.

Explanation or description

Another debate in science studies which is key for my study is one which focuses on the explanatory claims of SSK/the SP. There are two aspects to this. First, some critics (again, notably Peter Galison) challenge the validity of the "interest-theory account" or "social interests explanation" of SSK; second, more widely, others ask whether science studies can or should explain or (only) describe how scientific knowledge is produced.

Galison argues that some sociologists of science claim that theories are prior to belief, and that they carry this claim too far, such that they explain every scientific belief or commitment as satisfying earlier sociological interests. He claims that SSK holds that scientists accept or reject new scientific work on the basis of their interest in the future applicability of the skills which they have acquired through their scientific work. Galison argues that, by claiming that scientists' presuppositions, bolstered by their interests, condition the admissible phenomena, the strong form of the interest-theory account denigrates the role of nature.[68]

[68] Galison, op. cit., note 56: 10. Galison characterises Barry Barnes as arguing that social forces (alone) form knowledge; that a scientist does not gain knowledge by studying external nature. This representation

Galison argues that, although the conclusions to experimental arguments are not entirely logically impelled, experimenters' beliefs are not due entirely to interests.[69] He argues that theories are constrained by mathematical and physical considerations, and that experimentalists' conclusions are constrained by the skills and techniques of their work, which do not suddenly alter upon the introduction of new theory.[70] So, Galison cites Ian Hacking's statement that observation does not merely mean reading dials, what counts is the observer's picking out what is odd, unexpected, instructive or distorted in the operation of the equipment,[71] and Galison takes this as contradicting SSK.

Again, though, I think that Galison mis-represents the positions of Kuhn/SSK. SSK would not disagree with any of Galison's claims about the physical constraints on science and scientists. SSK does not claim that people's understandings of phenomena are shaped *only* by theories, nor that scientists' skills and techniques or the physical features of experimental apparatus have no influence upon findings or theories. But SSK does hold that experimentalists' beliefs and what they take as evidence are social constructs or social conventions.[72] SSK claims that how observers identify and distinguish what is odd from what is not odd is part of their tacit scientific knowledge. To make such identifications and distinctions, scientists draw on their community's similarity sets, and beliefs concerning which things exist and which do not, which things happen and which do not, which scientists learn as they learn science, and which are, therefore, socially constructed concepts.

---

of SSK is close to that of some scientists, such as those particularly involved in the "science wars," which I discuss later in this chapter.

[69] Experiments, he argues, are not like mathematics, so experimentalists' beliefs do not have the form of a mathematical proof, but experimentalists nevertheless reason, build and test their way to persuasive evidence.

[70] Galison, op. cit., note 56: 11.

[71] Ian Hacking (1983), *Representing and Intervening: Introductory Topics in the Philosophy of Natural Science*. Cambridge: Cambridge University Press: 230, cited in Galison, op. cit., note 56: 19.

[72] For SSK, beliefs, skills, techniques and evidence, while constrained by the physical world, are all theory-laden, and cannot be otherwise, but this is not a negative thing, this is how scientific knowledge is produced. To say that theory and belief are inseparable is not to set up a linear, causal relationship such that theory is the only thing which causes belief.

Bloor argues that the reason for the objections of some critics to SSK's interest explanations is because those critics assume that SSK takes interests to be rigid and pre-formed, a pre-existing set of social relations which the sociologist privileges above all other aspects and sees as determining the actions of social agents, who have no autonomy. Bloor, however, claims that the pattern of interests is not static and ahistorical; social processes are not static, nor are they external causes independent from the situation. Interests are grounded in interaction, so they change as scientific practice changes.[73] And scientific practice is constantly changing. Karin Knorr Cetina argues that social actors and the relations between them are made along with, and in accommodation to, their making of the material world of facts, phenomena and instruments. In tandem with the making of the material world, scientists transform or enhance themselves, for example by acquiring certain skills or tacit knowledges.[74] Thus, the practice of science transforms both the materials of science and scientists themselves and results in practitioners (scientists) with new skills and new interests.

Beyond the debate over whether interest explanations are valid is a wider debate over whether the strong programme should be explanatory or descriptive. As an example of this, see the dialogue between David Bloor and Michael Lynch, which revolves around their differing interpretations of Wittgenstein.[75] Bloor argues that Wittgenstein's analysis of rule-following (which holds that nothing in the formulation of a rule determines its next application) implies that there is a gap between rules and the practices which accompany them, and Bloor claims that this gap is filled by interests.

---

[73] Bloor, op. cit., note 40: 26.

[74] Karin Knorr Cetina (1992), 'The couch, the cathedral and the laboratory: on the relationship between experiment and laboratory in science', pp. 113-38 in Pickering, A (ed.), *Science as Practice and Culture.* Chicago and London: University of Chicago Press.

[75] Michael Lynch (1992a), 'Extending Wittgenstein: the pivotal move from epistemology to the sociology of science,' pp. 215-65 in Pickering, A (ed.), *Science as Practice and Culture.* Chicago and London: University of Chicago Press; David Bloor (1992), 'Left and right Wittgensteinians,' pp. 266-82 in Pickering, A (ed.), *Science as Practice and Culture.* Chicago and London: University of Chicago Press; Michael Lynch (1992b), 'From the "will to theory" to the discursive collage: a reply to Bloor's "left and right Wittgensteinians",' pp. 283-300 in Pickering, Andrew (ed), *Science as Practice and Culture.* Chicago and London: University of Chicago Press.

Lynch, however, points out that Wittgenstein argues that rules and practices are integrally related, so that understanding one means understanding the other. He argues, therefore, for the use of an ethnomethodological approach to explore and reveal the relation between scientific formulations and practices, and claims that wider social explanations are impossible; scientific practice carries its own principles by which scientists reach particular closures, through a process of "quiet agreement."[76]

This argument over explanation or description resonates for me with times during my MSc, when, as a new student of social science, I felt extremely uncomfortable, feeling that some social scientists were trying to be scientific by seeking to model social science along the lines which natural scientists claim that natural science follows. That is, it seemed to me that some social scientists were attempting to follow the ideology of natural science, how natural scientists represent science as being, rather than how, STS claims, natural science is actually conducted. So, at times, social science seemed to me to be more of the same as allopathic medicine, that is, to exhibit the attitudes with which I had been uncomfortable when studying allopathic medicine. Similarly, Sharon Traweek argues that the big explanatory frameworks of some schools of science studies are like those of the natural sciences,[77] while Hilary Rose points out that the way in which science studies tells its own origin story as a process of internal development with

---

[76] Lynch points out that Wittgenstein, like ethnomethodology, 'disavows science, theory and explanation,' saying that description should take the place of explanation (Ludwik Wittgenstein, *Philosophical Investigations*, #109, cited in Lynch (1992a), op. cit., note 75). Bloor responds that he does not feel it necessary to follow Wittgenstein in opposing theory, and argues that while ethnomethodology's descriptions of practice may contribute to SSK, they do not challenge its explanatory framework (Bloor, op. cit., note 75: 272; 274-5). So, for Bloor, SSK provides explanations for the descriptions of ethnomethodology. Bloor also points out that Lynch's "quiet agreement" is social, since agreement implies consensus, which is social, and which links rules and practices (Bloor, op. cit., note 75: 281). Lynch responds to this by arguing that this kind of consensus is so much part of the production of social order that it has little value as a discrete explanatory factor. He argues that while ethnomethodological "collages" may interact with SSK, since they explore all the facets of scientific knowledge production, they do not support a single social theory of knowledge such as "social interests" (Lynch (1992b), op. cit., note 75: 295; 299)

[77] Sharon Traweek (1992), 'Border crossings: narrative strategies in science studies and among physicists in Tsukuba Science City, Japan,' pp. 429-66 in Pickering A (ed.), *Science as Practice and Culture.* Chicago and London: University of Chicago Press: 430.

Kuhn as the founding father is, paradoxically, a non-social constructivist description.[78] That is, Rose argues, SSK does not apply its own theory to itself. These arguments link to wider debates associated with the social construction of knowledge, particularly those concerning the implications of social constructivism for the knowledge production of social scientists themselves, which I therefore next began to explore.

Engaged social constructivism

The criticisms of Traweek and Rose connect to a strong voice, stemming particularly from feminist and postcolonial theorists of knowledge, which objects to the perceived political neutrality of the SP. These theorists argue that the social constructivist position has political consequences, which should be explicitly addressed, that is, require some action on the part of theorists. I call this group of theorists (a group of people which includes feminists,[79] Indians,[80] Black Americans[81] and indigenous peoples from the Americas) "engaged social constructivists."

There has always been an explicitly political perspective to studies of the construction of scientific knowledge. Leo Marx argues that the positivist, modernist position has been disputed from its beginnings,[82] while pointing out that challenges to it

---

[78] Rose, op. cit., note 45: 11. Mario Biagioli makes a similar point, arguing that science studies avoids the implications of reflexivity (Mario Biagioli (1996), 'From relativism to contingentism,' pp 189-206 in Galison and Stump (eds.), *The Disunity of Science*: 190).

[79] See, for example, Donna Haraway (1997), *Modest_Witness@Second_Millenium.FemaleMan©_ Meets_ OncoMouse™: Feminism and Technoscience*. New York and London: Routledge, and Sandra Harding (1998), *Is Science Multicultural? Postcolonialisms, Feminisms and Epistemologies.* Bloomington, Ind: Indiana University Press (henceforth *ISM*).

[80] See, for example, Ashis Nandy (ed.) (1988), *Science, Hegemony and Violence: A Requiem for Modernity.* New Delhi and Oxford: Oxford University Press, and Vandana Shiva (1996), 'Science, nature and gender,' pp. 264-85 in Garry and Pearsall (eds.) *Women, Knowledge and Reality: Explorations in Feminist Philosophy,* 2nd edition. New York and London: Routledge. See also Gayatri Chakravorty Spivak (1988), *In Other Worlds: Essays in Cultural Politics*. New York and London: Routledge.

[81] See for example Patricia Hill Collins (1996), 'The social construction of Black feminist thought,' pp. 222-48 in Garry and Pearsall (eds.) *Women, Knowledge and Reality: Explorations in Feminist Philosophy,* 2nd edition. New York and London: Routledge, and also Collins' book (1991), *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment*. New York and London: Routledge.

[82] Leo Marx (1994/5), 'The idea of 'technology' and postmodern pessimism,' in Ezrahi, Y, Mendelsohn, E and H Segal (eds), *Technology, Pessimism and Postmodernism.* Amherst, MA: University of Massachusetts Press.

increased from the 1960s onwards, with the growth of the "new social movements" (NSMs) and "new religious movements" (NRMs).[83] As Hilary Rose points out, the Radical Science Movement[84] in the 1960s and '70s paralleled the shift in academic studies of science, since SSK developed contemporaneously with these critiques.[85] However, as I have indicated above, theorists from "classical" SSK (and many other scholars of science) tend to self-restrict to description; describing and explaining the processes whereby knowledge is produced, not (necessarily) explicitly and/or critically examining those processes. These kinds of scholars of STM describe how negotiations and debates over controversies take place, and how they are resolved, showing how the social interests of participants shape their acceptance or rejection of particular theories, and demonstrating the social factors in the construction of knowledge. They do not necessarily, therefore, (explicitly) address, nor question, the background cultural assumptions of scholars of science themselves, and so do not necessarily challenge the dominant, established view of knowledge.[86]

The argument that doing science studies is a political act is sometimes made in relatively narrow terms, such as in the 1990 debate on the politics of SSK between

---

[83] Despite being termed "new", these movements could in some ways be said to be reclaiming traditional ways of thought, what Thomas Torrance terms "classical" as opposed to "modern" thought (Thomas F Torrance (1985), *Reality and Scientific Theology.* Edinburgh: Scottish Academic Press). See also Karl Mannheim on conservative vs natural law (Karl Mannheim (1952), *Essays on the Sociology of Knowledge.* London: Routledge and Kegan Paul), and Bruno Latour's argument that "we have never been modern" (Bruno Latour (1993, translated by Catherine Porter), *We Have Never Been Modern.* New York and London: Harvester Wheatsheaf).

[84] Marxist analyses of natural science, which were oriented towards contesting existing science or "technoscience" in practice, for example, the Vietnam war. In the 1960s, theorists and activists (sometimes, but not necessarily, the same people) began to explicitly criticise positivism and the claim that "science works," arguing that science did not "work" for everything, nor meet the needs of everyone. Indeed, they pointed out, science often created needs and was frequently used for negative ends, for example in the industrial-military complex. These critics claimed that scientific knowledge and the scientific world view provided no solutions to the search for spiritual, non-material meaning, but rather denied any such need, defining it as superstitious and superfluous, and replacing any search for spirituality with the pursuit of material benefits and concrete, practical knowledge of the material and natural world, often serving interventionist ends (Marx, op. cit., note 82).

[85] Rose, op. cit., note 45: 6-7. Also see Harding, op. cit., note 79: 4-5.

Australian and British scholars of science, discussed further in the May 1996 special issue of *Social Studies of Science* on the politics of SSK. This debate centred on the principle of "methodological symmetry" and whether analysts of science should take sides in scientific controversies.[87] The political question for engaged social constructivists is much broader than this, however. Engaged social constructivists argue that the responsibility of the analyst is wider than the SP acknowledges, and state that, by describing only the social interests of those who are *actively* involved in producing scientific knowledge, the SP limits itself, since such a description can only be partial. Engaged social constructivists claim that the interests of those *excluded* from knowledge production equally contribute to the shaping of knowledge, precisely *because* of their absence,[88] and, as Sandra Harding, among many others, points out, this is a political issue.[89]

Engaged social constructivists hold that, having stated that knowledge is produced by people within particular social and cultural frameworks, the next step is to reveal who the producers of knowledge are, who is excluded, and the effects of this on how people come to define what knowledge is valid and acceptable. In particular, feminist theorists of knowledge argue that it is embodied people who produce knowledge, not disembodied minds detached from society or culture.

Engaged social constructivists therefore ask questions such as: whose voices are absent, who is not participating in knowledge production and/or scientific controversies,

---

[86] While questioning one's own taken-for-granted assumptions risks falling into extreme reflexivity, which is itself problematic, there is a point in recognising one's own limitations (identifying one's cultural blinkers), not least so as not to reproduce the exclusions of the groups being studied.

[87] So Pam Scott, Evelleen Richards and Brian Martin ((1990) 'Captives of controversy: the myth of the neutral social researcher in contemporary scientific controversies,' *Science, Technology and Human Values*, 15 (4): 474-94) argued that analysts of science should take sides with one or other of the groups engaged in a controversy, usually the "underdog," while Harry Collins ((1991) 'Captives and victims: comment on Scott, Richards and Martin,' *Science, Technology and Human Values*, 16 (20: 294-51) responded that the principle of methodological symmetry means that the analyst does not take sides; the analyst is not setting out to decide whose beliefs are right or wrong but investigating what each side believes and why.

[88] Brian Wynne (1988), 'Unruly technology: practical rules, impractical discourses and public understanding,' *Social Studies of Science*, 18 (1): 147-67.

which questions aren't being asked or answered, which knowledge is being ignored? That is, engaged social constructivists argue, speaking from the position of those voices which tend to be excluded, that the analyst should not restrict herself to asking what participants in a controversy believe and why, nor to siding with one or other side, but should (also) step back from the controversy to examine how the sides in a controversy have been constructed in the first place, who is participating, and who is not.[90]

Thus, engaged social constructivists extend social constructivism to argue for change. They argue that studies of science should contain an understanding of the broader context within which all scientific knowledge is produced, not merely the social context within which scientists themselves produce knowledge. They claim that merely describing scientific knowledge production, and reducing explanation to an abstraction of "interests," without fully exploring whose interests are represented and whose interests excluded, is not politically neutral, as claimed, but in fact, by not challenging the status quo, effectively (tacitly) supports it. Engaged social constructivists argue that, rather than taking the inequalities and exclusions which are part of the cultural context within which scientific knowledge is produced as givens, these too should be examined and highlighted, especially scientists' gender, "race" and class characteristics.[91]

---

[89] Harding, op. cit., note 79.

[90] The interests which are involved in controversy resolution (and knowledge production more generally) are not only the competing interests of the adherents to the different sides of a controversy, but also the interests of those groups who are excluded and so play no part in the controversy or in theory construction more generally.

[91] In *ISM* (Harding, op. cit., note 79: vii-viii) Sandra Harding argues that post-Kuhnian science studies have shown the links between scientific events and processes and their historical eras, examining the processes whereby scientific information became legitimated as knowledge and truth, and so revealing that scientific processes are social processes. However, she points out that, outwith feminist and postcolonial writings, there is as yet little (explicit) awareness of the gender, race and imperial dimensions of the historical eras with which science was integrated. See also Donna Haraway (1996), 'Modest witness: feminist diffractions in science studies,' pp 428-41 in Galison and Stump (eds.), *Disunity of Science*, and her discussion of Steven Shapin and Simon Shaffer's work on gentlemen scientists (Shapin and Schaffer (1985), *Leviathan and the Air-pump: Hobbes, Boyle, and the Experimental Life; including a translation of Thomas Hobbes, Dialogus physicus de natura aeris, by Simon Schaffer*. Princeton, NJ: Princeton University Press), and of Bruno Latour (1987, *Science in Action: How to Follow Scientists and Engineers Through Society*. Cambridge, Mass.: Harvard University Press), and her comments that they do not pay attention to the "raced" and gendered characteristics of scientists and (in Latour's case) scholars of science, whom he depicts as warriors engaged in trials of strength.

Thus, Evelyn Fox Keller discusses what she calls 'scientific subjectivity,' the construction of apparently agent-less knowledge, produced by an 'antisubject,' and points out that the absence of an authorial voice in scientific reports erases human agency, so removing any reminder of the "manmade" quality of science, the knowledge and human work which constructs science.[92] Keller's scientific subjectivity produced by an antisubject resonates with Sharon Traweek's comment that physicists construct 'an extreme culture of objectivity: a culture of no culture,'[93] an illusion of infinite vision which Donna Haraway calls the "god trick,"[94] or Thomas Nagel characterises as the 'view from nowhere.'[95]

Perhaps Kuhn reproduced this in his focus predominantly on "paradigms," that is, concepts or objects of thought, rather than the thinkers, as opposed to Fleck's focus on "thought collectives" (the people who possess the concepts). Focusing on knowledge rather than knowers conceals the characteristics of the knowers, thus implicitly reproducing the Enlightenment belief that knowledge and knowers are separate, detached one from the other, and that knowledge is disembodied.

Local knowledge and systematic patterns of knowledge and ignorance

Sandra Harding states that the central point for post-colonial, post-Kuhnian and feminist science and technology scholars is that, although some knowledge claims are more powerful than others, all knowledge systems are local, produced by particular people in particular places.[96] She points out that:

> The distinctive ways that cultures gain knowledge contribute to their being the kinds of cultures they are; and the distinctiveness of cultures

[92] Evelyn Fox Keller (1996), 'The dilemma of scientific subjectivity in postvital culture,' pp. 417-27 in Galison and Stump (eds.) *Disunity of Science*: 417.
[93] Sharon Traweek (1988), *Beamtimes and Lifetimes: The World of High Energy Physicists*. Cambridge Mass. and London: Harvard University Press: 162.
[94] Haraway, op. cit., note 3.
[95] Thomas Nagel (1986), *The View From Nowhere*. Oxford: Oxford University Press.
[96] Harding, op. cit., note 79: x.

> contributes to the distinctively "local" patterns of their systematic knowledge *and systematic ignorance* (my emphasis).[97]

Harding claims that 'the content of scientific knowledge is importantly shaped by interests in knowledge and interests in ignorance,'[98] and argues that different interests do not simply produce different pieces of a single puzzle, but that they may give rise to fundamentally incompatible knowledge claims. She asserts that cultures are both "prison houses" and "toolboxes" for the growth of scientific and technological knowledge, since cultural elements are crucial resources for growth of knowledge. That is, the forms of organisation of scientific research are culturally shaped; scientists draw on cultural concepts to use as metaphors and models for scientific theories; and the language-dependency of scientific accounts both enables and limits what a culture can know.[99]

Harding argues further that science studies projects which show the relationship between sciences and their societies fundamentally challenge the conventional "internalist epistemology."[100] Such studies, she says, show how sciences, while constrained in many respects by nature, "co-evolve" with their cultures.[101] She points out that cultures are located differently, historically and geographically, in nature, and, since nature is heterogeneous, cultures are exposed differently to different regularities of nature, and develop differently in relation to these. People's different interests, she argues, result in different interventions in nature, and thus in changes in nature, and they

---

[97] Harding, op. cit., note 79: 3.

[98] And points out that even the US National Academy of Sciences has said that the notion of scientific method can be broadened to include scientists' decisions about which problems to pursue and when to conclude an investigation (National Academy of Sciences, *On Being a Scientist*, Washington, DC: National Academy Press, 1989, 5-6, cited in Harding, op. cit., note 79: 66).

[99] Harding, op. cit., note 79: 20; 69.

[100] That is, that scientific knowledge works because of its internal features, that it is not culturally distinctive, that it does not reflect any social values or interests, that there is one nature, one truth about nature, and one science which reveals that truth (Harding, op. cit., note 79: 2-3).

[101] Harding, op. cit., note 79: 2-3. Harding chooses the term "co-evolution," rather than "co-construction" to describe the interlinking between knowledge and culture. Her term, she claims, emphasises how systematic knowledge-seeking is always just one element in any culture or society, transforming and being transformed by other elements (ibid.: 4).

also lead to different representations of nature, which in turn shape interests.[102] Further, people's different social interests and desires mean that they ask different questions about the "same" natural world, so that their differing interests produce differing patterns of knowledge and ignorance.[103] That is, different groups have different interests in learning about different parts of nature and these shape what each group counts as interesting questions, including scientific questions. Harding argues strongly that that what she calls the "universality claim" of natural science decreases valuable forms of cognitive diversity, by delegitimating any scientific problems which it does not find interesting,[104] and concludes that 'we can only imagine what patterns of knowledge could have been produced by cultures with interests different from those that directed the route of European sciences.'[105]

Harding argues, therefore, that postcolonial theory does not merely add new topics to conceptual frameworks, but challenges and transforms the frameworks themselves. She points out that, from the postcolonial position, the post-Kuhnian position can seem parochial; postcolonial theorists (such as those assembled in the

---

[102] Harding, op. cit., note 79: 67.

[103] For example, Harding cites Robert Proctor (1995, *Cancer Wars: How Politics Shape What We Know and Don't Know about Cancer.* Boston, Basic), and his argument that knowledge and ignorance about cancer have been shaped by the differing interests and power of the medical and environmental research lobbies (Harding, op. cit., note 79: 64-5).

[104] Harding, op. cit., note 79: 185. She argues that the universality claim makes it difficult to see the limitations which accompany the strengths of modern sciences, and so, although it is claimed that science advances through criticism, the universality claim effectively suppresses rather than encouraging criticism. Yet, she points out, scientific claims can never be regarded as once and for all proved or disproved, but only ever tentatively confirmed; any scientific framework eventually outlives its usefulness for the growth of knowledge (ibid.: 171). The pattern of ignorance resulting from modern sciences, Harding argues, is such that our knowledge focuses on discrete, isolated, short-term physical problems, which blocks our ability to see the social elements, and makes it especially hard to see distant, long-term, broadscale issues and changes (ibid.: 186). Harding goes on to point out that the ideology of Western science's "objectivity" internalises scientific benefits (which are claimed to result from the internal epistemological features of science), while externalising the costs (attributing these to (mis-) applications of technology/scientific knowledge), and legitimating the destruction of the environment and the movement of resources from less privileged to already privileged people (ibid.: 186-7).

[105] Harding, op. cit., note 79: 66. Within Europe itself, consider the folk knowledge which was destroyed with the murder of women defined variously as "witches" or "wise women."

collection edited by Ashis Nandy[106]), ask epistemological questions from outside the Euro-American intellectual tradition and demonstrate the links between European expansionism and European scientific and technological growth, and the effects of these processes on non-European peoples.[107] Postcolonial theorists reject the role of disinterested observers of sciences in history, but instead engage with debates over representations of nature and over science and technology policy.[108]

Objectivity, realism, relativism and reflexivity

Similarly, feminist theorists also challenge conceptual frameworks, not only concepts within those frameworks. Belenky et al. claim that "women's ways of knowing," in particular what they call "connected knowing," challenge the dualisms between mind-body, rational-emotional, nature-culture, men-women, and so on, which are unquestioned by, and implicit in, most of science, and arguably also mainstream SSK.[109] Feminist theorists seek to integrate these dualities, to challenge the claim that "objectivity" in the form claimed by natural science is possible, in part by showing that other conceptualisations exist.[110]

There are broadly two different perspectives on how to replace existing canonical knowledge and knowledge claims.[111] On the one hand feminist standpoint theory holds that what feminists should do is produce better and truer pictures of reality; give new

---

[106] Nandy, op. cit., note 80.
[107] Harding, op. cit., note 79: 4; 6-7.
[108] Harding, op. cit., note 79: 8. So, for example, Vandana Shiva highlights the Western secular cosmological understandings which underpin scientific knowledge (Shiva, op. cit., note 80). On this point, see also Ashis Nandy (op. cit., note 80) and Shiv Visvanathan (1997), *A Carnival for Science: Essays on Science, Technology and Development*. Oxford and New Delhi: Oxford University Press.
[109] See Mary Belenky, Blythe Clinchy, Nancy Goldberger, and Jill Tarule (1986), *Women's Ways of Knowing*. New York: Basic Books, and also Nancy Rule Goldberger, Jill Tarule, Blythe Clinchy and Mary Belenky (eds.) (1996), *Knowledge, Difference and Power: Essays inspired by Women's Ways of Knowing*. New York: Basic Books. Also see Carol P MacCormack and Marilyn Strathern (eds.) (1980), *Nature, Culture and Gender*. Cambridge: Cambridge University Press, and note Pickering's claim (mentioned above) that studies of science as practice also do this.
[110] See Vandana Shiva's argument against "the ontology of dichotomisation," where she indicates that in Indian cosmology person and nature are a duality in unity, inseparable complements of one another.(Shiva, op. cit,, note 80: 282).

meanings to "reason" and "objectivity." On the other hand, feminist postmodernism holds that universalising discourse is impossible, so it should be replaced with localised, reliable feminist knowledges.

As an example of the former, Harding claims that identifying the eurocentric and androcentric elements which are present both in the conceptual frameworks of science and technology and also in the conceptual frameworks used to think about them (such as SSK) will lead to better objectivity of understandings of European sciences and technologies, of the systematic knowledges of other cultures, and of the links between them. However, she argues, accepting that knowledge claims are socially and historically relative does not entail epistemological, judgmental relativism.[112]

Instead, Harding argues for a form of objectivity which she calls "strong objectivity." She states that she does not want to reject the possibility of objectivity (that is, knowledge which is more than just opinion), but wants to strengthen the concept. She criticises the traditional concept of objectivity as "weak," since, she argues, it applies only to the "context of justification" (research methods) not to the "context of discovery" (the definition of research problems and hypotheses). The context of discovery is seen as unexaminable by science, yet, she claims, it is here that values most obviously enter scientific knowledge. Thus, ignoring the context of discovery sustains the myth of scientific neutrality.[113]

So Harding challenges the link between detachment and objectivity, and, as Rose points out, naming the orthodox form of "objectivity" as "weak" is a powerful move, which challenges the foundations of scientific claims to objectivity.[114] Other theorists

---

[111] Rose, op. cit., note 45: 23. See Rose's chapter 4 for further discussion of this debate.
[112] Harding, op. cit., note 79: 18-9. Similarly, Bloor points out that while it is a form of relativism to examine all beliefs as if they are equally problematic in terms of why scientists believe them, this is not the same as saying that all beliefs are of equal worth. However, it does mean that the *credibility* of all beliefs may be explained in terms of local, contingent causes (Bloor, 'The sociology of scientific knowledge,' op.cit. note 40: 19 (citing Barry Barnes and David Bloor (1982), 'Rationality, relativism and the sociology of knowledge,' pp. 21-47 in Hollis, M and Lukes, S (eds.), *Rationality and Relativism*. Oxford: Blackwell)).
[113] Sandra Harding (1991), *Whose Science? Whose Knowledge?* Milton Keynes: Open University Press.
[114] Rose, op. cit. note 45: 93.

have similarly challenged these claims. Harding's "strong objectivity" is close to Donna Haraway's "situated knowledge," on which I have drawn for the title of this chapter.[115] Opposing situatedness to detachment, Donna Haraway argues that people produce knowledge from their particular situation and location in relation to society, and that: 'both the objects and the subjects of knowledge-making practices must be *located.*' Location, Haraway argues, is not self-evident, is always finite, and always partial, both in the sense of being incomplete and also: 'in the sense of being for some worlds and not others. There is no way around this polluting criterion for strong objectivity.'[116]

Likewise, Lorraine Code argues that what she calls a realist, rational and 'significantly objective' relativism neither accepts the traditional absolutist-relativist dichotomy, nor the opposition between relativism on the one hand, and realism, rationality and objectivism on the other. Her 'significantly objective' relativism, Code says, recognises that rationality and objectivity have never provided the certainty their proponents would claim.[117] She states that there are only a very few 'artificially isolated and purified empirical knowledge claims' for which necessary and sufficient conditions hold which would apply to any knower regardless of their subjectivity.[118] Code claims that realism and relativism are not incompatible, and argues that epistemologists should take subjective factors relating to the knower into account, yet locate these in the wider social context, so preserving a realist commitment, and not becoming subjectivist.[119]

Perhaps in part the multiple terms for the reflexive or relativist position are symptomatic of the negative perceptions of relativism, and the associated misrepresentation of and attacks on science studies.[120] Other theorists of social

---

[115] Haraway, op. cit., note 2. Other terms which Haraway has used for this concept include "diffraction," "critical reflexivity" and "embedded rationality."
[116] Haraway, op. cit., note 91: 440.
[117] Lorraine Code (1996), 'Taking subjectivity into account,' pp. 191-221 in Garry and Pearsall (eds.) *Women, Knowledge and Reality: Explorations in Feminist Philosophy,* 2nd edition. New York and London: Routledge: 213.
[118] Ibid.: 191.
[119] Code, op. cit., note 118: 196.
[120] From outwith science studies relativism is associated with the caricature that science studies claims that society shapes nature (as discussed above in relation to the "Science Wars"), while, from within science

constructivism (such as those who argue the disunity of science position and/or for the study of science as practice) have also coined new terms to describe what is effectively a relativist position, and so, effectively, tacitly accept the negative caricature of relativism. So, for example, Mario Biagioli coins the term "contingentism,"[121] and Pickering and Stephanides claim that they are arguing for 'a culturally situated historicity.'[122]

---

studies, it is often associated with the move by some theorists to what others perceive as extreme reflexivity. For examples of especially reflexive theorists, see Steve Woolgar (1988) (ed), *Knowledge and Reflexivity*. London: Sage; Steve Woolgar (1988), *Science: The Very Idea!* London: Tavistock; Malcolm Ashmore (1990), *The Reflexive Thesis.* London and Chicago: University of Chicago Press. As an example of criticisms from within science studies, see Donna Haraway's comment that Steve Woolgar has been read as being unable 'to get beyond self-vision as the cure for self-invisibility' (Haraway, op. cit., note 91: 436). Also see the debate between, on the one hand, Steve Woolgar (arguing for extreme reflexivity) and, on the other, Harry Collins and Steven Yearley (arguing that there is no point to reflexivity, that it is more interesting to focus on the social contingency of natural science) (Harry Collins and Steven Yearley (1992a), 'Epistemological chicken,' pp. 301-26 in Pickering, A (ed.), *Science as Practice and Culture*; Steve Woolgar (1992), 'Some remarks about positionism: a reply to Collins and Yearley,' pp. 327-42 in Pickering, A (ed.), *Science as Practice and Culture*; Harry Collins and Steven Yearley (1992b), 'Journey into space,' pp. 369-89 in Pickering, A (ed.), *Science as Practice and Culture*).

[121] Thus, Biagioli, despite arguing for located knowledge, and pointing out that for ethnomethodologists reflexivity is not a problem but part of its method, accepts the negative characterisation of relativism as an over-reaching universal claim (Biagioli, op. cit., note 77: 206). Biagioli draws a parallel with evolutionary theory, stating that a representation of reality is neither good nor bad but contingently effective or ineffective, such that what survives is the good enough, not necessarily the best, representation (ibid.: 199). Of course, drawing on a scientific theory as an analogy is a step which itself raises questions. For new terms for relativism see also David Stump (1996), 'From epistemology and metaphysics to concrete connections,' pp. 255-85 in Galison and Stump (eds.), *The Disunity of Science*: 256. Similarly, although Arthur Fine states that scientific facts, practices and opinions are neither essentially objective nor essentially social, but locally particular, he concludes that there is neither global truth nor global relativism, and introduces various terms to express his position, such as the "natural ontological attitude" (NOA) and "methodological constructivism" (which he opposes to "metaphysical constructivism") (Arthur Fine (1996), 'Science made up: constructivist sociology of scientific knowledge,' pp. 231-54 in Galison and Stump (eds.), *The Disunity of Science*: 249; 254).

[122] Pickering and Stephanides, op. cit., note 66: 163. They argue that scientists' struggles with resistance 'structure the cultural space in which interests are constructed and pursued,' and that exploring these struggles 'makes it possible to get to grips at once with the objectivity and relativity of scientific knowledge,' pointing 'both beyond and toward a historicist understanding of science' rather than appealing to a principle which is claimed to transcend time (standards for "objectivity;" interests for "relativity"). They argue that their construal of objectivity is such that revealing the contingency and situatedness of scientific knowledge does not deny its objectivity (ibid.: 164). They claim that they are seeking 'to dissolve stereotypical oppositions between objectivity, relativity and historicity,' and so to offer 'a unitary understanding' of the objectivity, relativity and historicity of scientific knowledge, rather than holding that 'unsituated normative or explanatory concepts like criteria or interests' structure practice from without (ibid.: 164-5, footnote 26).

Excluded knowledges

Engaged social constructivists do not merely note that knowledge is relative, contingent or situated, but extend this to argue as follows: (i) if knowledge is socially constructed (that is, if knowledge reflects the beliefs and interests of those who produce it), and (ii) if those who produce it are overwhelmingly the dominant minority of people (White, Western (or Westernised), middle-class and male), then (iii) current knowledge is limited (since a minority of people produce it and it reflects only their beliefs and interests), and knowledge could be produced differently. This opens out the possibility that the production of knowledge could (or should) be democratised such that the perspectives of currently excluded groups were represented, and such that, within the process of knowledge production (Harding's "context of discovery") questions were asked such as what STM is for and what its goals are (or, as Susan Leigh Star asks: *cui bono?* or, for whose benefit?[123]). The consequence of this would be a radical change in our current understanding and production of knowledge, in terms both of its aims and of its content.

These arguments concerning the purpose served by both scientific knowledge production and by studies of such knowledge production resonate with my own "what for?" – the question with which I first came to science studies – and also link to Nicholas Maxwell's courageous move from within orthodox history and philosophy of science to ask what knowledge is for, and to argue that the academic enterprise should aim to accumulate not knowledge (that is, scientific facts), but wisdom (which includes explicitly taking into account the ends for which those scientific facts are intended).[124]

Thus, underlying these arguments is the profoundly radical critique and argument that "something is missing." Engaged social constructivists argue for a kind of knowledge which includes (and validates) those knowledges which science, technology

---

[123] Star, op. cit., note 60.

[124] Nicholas Maxwell (1984), *From Knowledge to Wisdom.* Oxford: Blackwell. Maxwell's move was courageous since his argument has been much derided by other philosophers of science. Mary Midgley

and allopathic medicine as currently constructed exclude. The unexamined assumptions underpinning science and scientific knowledge as currently constructed include social structures which exclude groups such as women and bodies of systematic knowledge which are not Western, nor scientific. The aim of engaged social constructivists is then to reclaim the excluded issues and knowledges which scientific knowledge was constructed to exclude (and by excluding).

That is, for engaged social constructivists, social constructivism is a theory which has implications for action (practice) by those who hold it,[125] and engaged social constructivists carry this argument through from theory to practice. Engaged social constructivists seek to include elements and understandings in knowledge which are excluded by dominant understandings of knowledge. So, the engaged social constructivist approach to research seeks to "strengthen" objectivity by explicitly acknowledging its subjective component, that is, by "situating knowledge,"[126] such that the theorist or analyst of knowledge also has a responsibility to explicitly locate herself.

The engaged social constructivist approach also relates to topics for research, and at the outset of this project I felt that there were two main areas of knowledge which related particularly to my thesis: spiritual knowledges, and the experiential skills and/or knowledge acquired by women. As Hilary Rose argues, women's relational skills are both undervalued and denied any social character.[127] Even where these skills are acknowledged, such as in nursing, the acknowledgment does not come in terms of status

---

cites Maxwell when she argues along similar lines (Midgley (1989/95), *Wisdom, Information and Wonder: What is Knowledge For?* London: Routledge).

[125] So too is Cicely Saunders' theory of "total pain," see later in this chapter.

[126] As a few examples of discussions of feminist social scientific research methods, see Dorothy Smith (1997), *The Everyday World as Problematic: A Feminist Sociology*. Milton Keynes: Open University Press; Mary Maynard and June Purvis (eds.) (1994), *Researching Women's Lives from a Feminist Perspective*. London: Taylor and Francis; Liz Stanley and S Wise (1993), *Breaking Out Again: Feminist Ontology and Epistemology*. London: Routledge.

[127] Rose, op. cit., note 45: 37. See also Rose's comments on how Marx's insistence on the social division of labour being between mental and manual ("hand" and "brain") entirely missed the labour of the "heart," which is particularly characteristic of women's work (ibid.: 30).

or financial rewards. Women's nurturing qualities may be praised, yet simultaneously treated as innate not acquired knowledge and nor, therefore, scientific.[128]

Thus, I began this study with understandings of research drawn from engaged social constructivism, and built on these in relation to my own research (that is, my own production of knowledge). The engaged social constructivist position framed and guided my approach to my research, both my initial approach to the theory of knowledge and also my fieldwork, situating both my activities (participation) in St Z's, and also my subsequent production of knowledge relating to the situatedness of workers' knowledges, beliefs and practices, and throughout this chapter I have tried to situate my theoretical argument.

However, after completing my fieldwork, I found it difficult to see how the areas of theory which I had studied before beginning my fieldwork helped with my analysis. In particular, I needed a way to think about gaps between theories and practices. I therefore returned to look more closely at the literature on science as practice and the disunity of science, and through doing so I became increasingly aware of the multiple, contradictory interpretations of Kuhn. I therefore returned to the original texts to clarify for myself what Kuhn had said, and found his discussion of what he called the "disciplinary matrix" useful. I will therefore now move on to discuss this.

KUHN'S "DISCIPLINARY MATRIX"

Kuhn is often associated with the term "paradigm," which has become widely used. However, its use is often unclear, with overlapping and sometimes contradictory meanings. I find the term "paradigm" confusing, both in Kuhn's usage (as he later elaborated, he was using it in two senses), and also in how people currently use it, where

[128] Thus, Project 2000, which aimed to conduct nursing training within university setting, validated nurses' knowledge in terms of established academic, scientific approaches to knowledge, rather than validating women's skills and experiential knowledge.

(perhaps partly owing to Kuhn's confusing usage) it is used to mean various concepts, which are not always the same, nor are they always equivalent to what Kuhn meant.[129]

The process of changing scientific theories, which Kuhn called scientific revolution, is often referred to as "paradigm shift," but Kuhn never used "paradigm" in the sense of "theory." Kuhn used "paradigm" in two senses: both to stand for the constellation of beliefs, values and techniques shared by members of a given (scientific) community (this meaning might be paraphrased as the scientific community's "world view"), and also for one particular element in that constellation: the concrete puzzle solutions which serve as models for solving further scientific puzzles.[130]

Although paradigms in this latter sense of puzzle solutions change when a theory changes, this meaning of paradigm is more restricted than that generally implied in the phrase "paradigm shift." Conversely, the use of the term "paradigm shift" in the rather vague sense of world view is problematic, since, if a "paradigm" is the whole set of beliefs, values and techniques to which a community subscribes, it is then difficult to know quite when a new paradigm can be said to be formed, since some parts of the constellation of the community's beliefs, values and techniques could (and usually do) change while leaving other parts unchanged. A scientific community seldom, if ever, changes *all* of its beliefs, values and techniques (the whole of its world view) when it changes a theory.[131] The question then (therefore) arises of how much of a change, and of which parts of the paradigm, would be necessary to create a new paradigm in its broad sense.

Thus, "paradigm" is a problematic term, and Kuhn was aware of the problem of its multiple uses and meanings as early as 1969, when, in his postscript to the 2nd edition of *SSR*, he elaborated on what he meant by the term. He pointed out that his original use of "paradigm" was unclear, since he had used it to stand for two concepts,

---

[129] See, for example, Jessica Corner (1996), 'Is there a research paradigm for palliative care?' *Palliative Medicine*, 10: 201-8. The use of "paradigm" here relates to neither of Kuhn's terms, neither puzzle solution nor disciplinary matrix, but means something closer to consensual approach.

[130] Kuhn, op. cit, note 4: 175.

and so "paradigms" (model puzzle solutions) were part of a "paradigm" (a constellation of beliefs, values and techniques).[132] Kuhn proposed that "paradigm" should be restricted to his narrower meaning: an exemplar, or a concrete model solution to a question or puzzle (this is equivalent to the dictionary definition[133]). Owing to the potential confusion from using "paradigm," however, I will use the term "exemplar" for this latter meaning.

For the wider meaning of "paradigm": the collection of beliefs, values and techniques to which a scientific group or community is committed,[134] Kuhn suggested using the term "disciplinary matrix," and this was a concept which he developed in the 2nd edition of *SSR*. He asserted that scientists in every scientific discipline share a disciplinary matrix, which he defined as a constellation of beliefs, values and techniques, with four components: (i) *exemplars* (or "paradigms" in the narrow sense); (ii) *symbolic generalisations* (for example, formulae or equations, such as (for physics) $f = ma$; or (for chemistry) $CH_4 + 2O_2 \rightarrow CO_2 + 2H_2O$); (iii) *values* and (iv) *metaphysical paradigms*: beliefs (such as that all perceptible phenomena are due to the interactions of atoms) which supply possible analogies and metaphors for the scientific community, and which include a scientific community's definitions both of those entities which it takes to exist (such as atoms or subatomic particles) and also (by implication) of those entities which it takes as not existing, such as spirits. By defining which entities the community takes as existing (and which entities, by implication, it does not), metaphysical paradigms

---

[131] See Galison, discussed on pp. 22-3 above.

[132] In addition, the wider meaning of paradigm produces, as Kuhn said, a problematic circularity, since, for this meaning of the term, a paradigm is what a scientific community shares, yet a scientific community is defined as a group of people who share a paradigm (Kuhn, op. cit., note 4: 176). Thus, for this meaning of paradigm, each of the terms "paradigm" and "scientific community" defines the other.

[133] The OED (1978) defines paradigm as an example or pattern, especially of inflection of noun or verb, deriving from Greek, *paradeigma:* show side by side (*para:* beside; *deiknumi:* show).

[134] Kuhn, op. cit., note 4: 182. It's worth noting, however, that by using the term "disciplinary matrix" Kuhn did not resolve the problem with a circular definition which he identified in relation to the term "paradigm," since, equally, a scientific community shares a disciplinary matrix and a disciplinary matrix is that which a scientific community shares.

contribute to the decisions of scientists in a particular community concerning which explanations or solutions are acceptable).

Thus, Kuhn's disciplinary matrix includes multiple factors which combine to shape both scientific theories and also scientific knowledge more broadly (including the scientific community's decisions concerning which knowledge is valid and which invalid). Within the context of its disciplinary matrix, the scientific community produces, judges and develops theories. If the scientific community replaces a particular theory with another, this may also entail changes in some, but not all, of the elements of its disciplinary matrix, most frequently exemplars.

I find "disciplinary matrix" a far preferable term to "paradigm,"[135] because of its multi-dimensionality, which makes sense to me, providing a more detailed tool for exploring the detail of systems of thought. In addition, because the term is used less frequently than paradigm, it is far less open to mis- or multiple interpretation. (In relation to this latter point, I think that Kuhn's term "metaphysical paradigms" is potentially confusing, since it includes the problematic term "paradigm," and I therefore rephrase the term as "metaphysical models").

The four components of the disciplinary matrix

As I have said, Kuhn argued that the term paradigm should be restricted to one element of the disciplinary matrix: an *exemplar*, that is, a concrete model for a puzzle-solution. He claimed that scientists learn from exemplars to group objects and situations into similarity sets, without having to explicitly ask "similar with respect to what?" Kuhn

[135] The term *Denkstil*, "thought style," which Ludwik Fleck used to mean 'that which sociologically conditions cognition within the thought collective,' (Trenn et al, preface to Fleck, op. cit., note 5: xv), also implies a single factor, and, as with paradigm in its wider sense, I find this concept too global (and therefore too vague) to be useful when looking at the detail of what scientists take to be valid scientific knowledge, and for what reasons. Trenn et al say that Mannheim introduced the term *Denkstil* in 1925, but that *Denkkollektiv*: 'thought collective,' was possibly Fleck's own coinage, although they emphasise that his idiosyncratic writing style makes the original text difficult to follow, and so call their translation of Fleck "interpretative," seeking to emphasise that their translation seeks to remain faithful to Fleck's complex ideas while trying to make them readable.

argued that, through this process of learning to perceive situations as similar to other situations, scientists also learn to solve problems by modelling them on previous puzzle-solutions for "similar" situations. Kuhn claimed that scientists learn about nature and words for nature at the same time as they learn concrete examples for the use of this knowledge, and Kuhn argued that generalisations of scientific laws can only begin to function after scientists have learned something, *prior* to those laws, about what their community understands to be situations which nature does or does not present.

Kuhn claimed that via this process of learning through exemplars to perceive particular situations and their solutions as similar to other situations and solutions, scientists end up with what Michael Polanyi called "tacit knowledge"[136] about science, which is gained by and through doing science rather than by explicitly acquiring rules for doing it.[137] Nevertheless, Kuhn asserted that, although there are no rules, in the sense of complete sets of criteria, for why scientists group particular situations into similarity sets, this does not mean that scientists have no system for that grouping, and scientific knowledge is still systematic, despite its lack of complete sets of (explicit) rules.[138]

Kuhn's argument implies that for someone to become an accepted, recognised, professional scientist (that is, to become a member of a scientific community), they have to have learnt the taken-for-granted similarity sets with which their scientific (disciplinary) community operates. They then apply these similarity sets systematically to future situations which they encounter (and other members of their disciplinary community judge how well they do this), and they rarely, if ever, explicitly consider the basis on which they do so.

---

[136] Michael Polanyi (1958), *Personal Knowledge: Towards a Post-Critical Philosophy.* London: Routledge and Kegan Paul.

[137] Kuhn, op. cit., note 4: 191. Kuhn stated that when science students do scientific problems they are doing something more complex than simply practising how to apply theory. By doing problems, the student learns things about the community's understandings of nature, and learns how to identify resemblances between a new problem and one previously encountered. Model problems serve to develop a student's ability to perceive various situations as being like each other, and so s/he assimilates the group's way of perceiving the situations that confront them as scientists (ibid.: 189).

[138] Kuhn, op. cit., note 4: 192.

In this participatory, non-explicit fashion, scientists also absorb values and metaphysical models into their body of (tacit) knowledge. Kuhn claimed that scientists from different scientific disciplines share values and metaphysical models more commonly than they share any of the other components of the disciplinary matrix, and emphasised that scientists share *values for* rather than *rules for* doing science. He argued that the values which scientists share include that scientific theories should be accurate, plausible, simple, and consistent, but that chief among scientific values is that theories should permit puzzle-formation and enable puzzle-solving, that is, that science should have an instrumental/predictive function, and that predictions should be accurate, and preferably quantitative (which preference for quantitative, accurate predictions, Kuhn claimed, was the most deeply held of all scientific values).[139]

Scientists' sharing of values for science rather than rules for doing science, Kuhn argued, facilitates flexibility and change in scientific theories, since values are more open to interpretation than are rules. Kuhn pointed out that, while scientists (and, I would add, people more generally) may share values, they apply them differently, that is, they differ in their understandings of concepts such as "simplicity," "consistency," and "plausibility." Thus, what one person identifies as an insupportable inconsistency in a theory may be perceived by others as merely a difficulty, resolvable within the theory.

Kuhn held that, because of the differences in how people apply values, a person or group of people is not making a mistake or being unscientific by adhering to a particular theory, but that, because of these differences, scientific communities do not *systematically* decide between competing theories. Instead, Kuhn claimed that a community of specialists decides to favour one set of arguments over another on the basis of how those arguments interact with the community's particular sets of shared

[139] Kuhn, op. cit., note 4: 182-5. Kuhn also noted that some scientists' values also include that sciences should be socially useful, although other scientists hold that science need not be (directly) useful to society.

values and experiences,[140] that is, on the basis of how the arguments for a particular theory fit with the community's disciplinary matrix.

Kuhn claimed that the governing of theory choice by shared values rather than shared rules is what ensures the long term success of science, since the flexibility of people's interpretations of the values which they share enables theory change.[141] He argued that the individual variability in how people apply values facilitates both change and stability: scientists do not all respond to all anomalies as sources of crisis, nor do they all embrace all new theories. However, some scientists identify some anomalies as particularly problematic for existing theories, and therefore seek new theories to explain these anomalies. This may then result in scientific revolutions (that is, the general acceptance of new scientific theories).

Implications of Kuhn's disciplinary matrix

Kuhn's analysis of science can be applied to allopathic medicine, since allopathic medical practitioners claim/strive to be scientific, that is, to model their practice along the lines which the ideology of science claims that scientific practice follows.[142] I think that practitioners of both natural science and allopathic medicine share disciplinary matrices both within and between the scientific/disciplinary communities to which they belong. These disciplinary matrices contain values, metaphysical models, symbolic generalisations (which allopathic medicine frequently draws from fields such as biochemistry) and exemplars. Both natural science and allopathic medicine have similarity sets which new members of the community learn by being shown,[143] and

---

[140] Kuhn, op. cit., note 4: 200.
[141] Kuhn, op. cit., note 4: 185-6.
[142] Although allopathic medical practice is frequently not based on evidence, as highlighted by the current move to "evidence-based medicine" and also "evidence-based nursing."
[143] See for example Paul Atkinson (1981; 2nd edition 1997), *The Clinical Experience: The Construction and Reconstruction of Medical Reality.* Aldershot and Brookfield, Vermont: Ashgate, and also Byron J Good and Mary-Jo DelVecchio Good (1993), '"Learning medicine": the constructing of medical knowledge at Harvard medical school,' pp. 81-107 in Shirley Lindenbaum and Margaret Lock (eds), *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life.* Berkeley, Los Angeles, London: University of California Press.

allopathic medical facts are similar to facts in natural science, since both science and allopathic medicine implement theories in practice, applying, testing and developing them through periods of what Kuhn called "normal science" (or "normal" allopathic medicine). Thus, when I discuss scientific communities I include those from allopathic medicine.

Kuhn's disciplinary matrices are specific to particular disciplinary communities, so that the disciplinary community in a particular field of science or allopathic medicine shares specific exemplars and symbolic generalisations. These elements of the disciplinary matrix are more foregrounded than values or metaphysical models, and so are more explicitly shared by members of the disciplinary community (although this may be less the case for long-standing exemplars or symbolic generalisations, which may be taken as given). So, for example, people in different allopathic medical specialties share an understanding (or an exemplar) that a particular set of signs and symptoms equals a particular disease, and share symbolic generalisations, such as those relating to the mechanism of action of particular pharmaceutical agents. Thus, exemplars and symbolic generalisations are more local to particular disciplinary communities.[144]

However, not all the components of disciplinary matrices are unique to each scientific community. Kuhn claimed that some components – in particular, values and metaphysical models – of the disciplinary matrix are shared both within and between the different specialties in natural science, and I suggest that this is the same for allopathic medicine. So, for example, various metaphysical models for allopathic medicine include: that disease results from inflammation, infection or genetic causes, that is, that external processes/agents are the causes of ill health;[145] that the mind and body are separate[146] (although some people in some allopathic medical specialties increasingly accept that they affect each other – see, for example, the recent move towards the

[144] Although, if explained, they are still comprehensible to people in other scientific or allopathic medical communities.

[145] Hence, as I mentioned in chapter 1, the term allopathic, from the Greek *allos*: other.

"biopsychosocial,"[147] the relatively new field of psychoneuroendocrinology,[148] and, in relation to cancer, the growth in "psychosocial oncology"[149]); and that the spirit (even if such a thing is taken to exist) is also separate, and so not an entity for consideration by allopathic medicine as a scientific discipline (although, as with natural scientists, individual allopathic medical practitioners may have personal spiritual and/or religious beliefs and practices).[150]

In addition, I think that some values for natural science are also values for allopathic medicine. Kuhn argued that puzzle-solving was a key value for science. Similarly, a key value for allopathic medicine is being problem-focused, seeking to solve problems and deliver associated solutions or "interventions." Allopathic medical practitioners determine which interventions they consider appropriate on the basis of allopathic medical theories, which are constructed and exist within particular disciplinary matrices, and are therefore linked to metaphysical models and values.

Kuhn argued that other key values for science were accuracy, plausibility, simplicity and consistency, and, associated with the key puzzle-solving value, he claimed that the most deeply held scientific value was the preference for accurate, preferably quantitative, predictions. I suggest that another scientific value (which perhaps frames those which Kuhn identified) is that which engaged social constructivists highlight: detachment/objectivity: the claim that producers of knowledge produce knowledge independently of themselves; who they are has no effect on the knowledge which they

---

[146] Lawrence J Kirmayer (1988), 'Mind and body as metaphors: hidden values in biomedicine,' pp. 57-93 in M Lock and DR Gordon (eds.), *Biomedicine Examined.* Dordrecht, Boston and London: Kluwer.
[147] David Armstrong (1983), *Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century*. Cambridge: Cambridge University Press.
[148] See the journal *Psychoneuroendocrinology* (published by Elsevier), which focuses on the relationship between psychological issues, neurological issues, and endocrine function.
[149] See for example the journal *PsychoOncology*, associated with the British Psycho-Oncology Society.
[150] An example of an alternative metaphysical model and associated approach is that of Ayurvedic medicine, which holds that ill health results from imbalance in what is taken to be a person's naturally healthy balance of all facets of their life, including physical, emotional, social and spiritual factors. Ayurvedic practitioners, therefore, seek through their treatments to restore this balance (see, for example, Robert E Svoboda (1992), *Ayurveda: Life, Health and Longevity*. London: Penguin or Vasant Lad (1985),

produce, and that science is (and should be) external to and separate from both the natural world and society, and that this separation enables the scientific method to produce theories about the (natural) world, theories which reveal how the world is. Associated with this is another, similarly encompassing, value: neutrality, and a third, related value: that what matters for science is what (and only what) can be investigated via the scientific method.

This latter value facilitates the predictive and problem-solving values of scientific knowledge, and linking to these, a key metaphysical model holds that what can be investigated is what exists, and frequently extends this to its inverse, such that what *cannot* be investigated *does not* exist (or, for the purposes of science, can be taken not to exist). Thus, for example, according to this metaphysical model there is no spiritual dimension, or, if there is, it is outwith the realm of science, and therefore science does not need to address it; other fields and disciplines, such as theology, can do so.[151] In this way, intangibles such as "the spirit" and "spirituality" are excluded from science, and this, in association with the exclusion of subjectivity via the valorisation of objectivity, means that the uncertainty associated with subjectivity and intangible concepts is also excluded from science. In turn, this underpins other values for science, in particular the puzzle-solving value.

However, precisely because a scientific community's disciplinary matrix includes its members' values and metaphysical models, the apparent certainty of science is in part grounded in articles of belief/faith, which exist in the background and are seldom examined or made explicit. Scientists do not hold values and metaphysical models as explicitly as exemplars or symbolic generalisations. Instead, these elements of the disciplinary matrix form part of the taken-for-granted background against or within which scientific or allopathic medical practice is conducted, across multiple disciplines.

Ayurveda: The Science of Self-Healing. Santa Fe: Lotus Press). I will consider this further in my discussion chapter (chapter 6).

Theory change and the disciplinary matrix

Linking to this underlying issue of belief or faith, Kuhn argued that a kind of "conversion experience" led to scientists choosing a new theory over an existing one. The question then arises of how people are converted to new theories. The first stage is presumably that people feel uncomfortable with the accepted theory, that is, with current "normal science." Which people feel uncomfortable? What is the source of their discomfort?

Fleck argued that "marginal men," people who participate in more than one thought collective (or disciplinary community), produced new theories and/or were more likely to be converted to new theories. They were marginal in the sense that they were on edge of several thought collectives (or disciplinary communities), and so on the boundaries between them. Similarly, as I have discussed, Galison claims that new theories emerge in "trading zones" between existing scientific disciplines, where scientists revise theories from their disciplines of origin.[152] These new theories may then co-evolve with new disciplines or specialties which form within trading zones, while within the old disciplines the old theories are not fully replaced, but persist. That is, people on the margins, or people in trading zones between disciplines, who adhere less strongly to the existing, previously dominant theory, are more able to take on the full implications of a theory change, while those at the centre do not necessarily do so. So new theories may co-evolve with new specialties (scientific disciplines) so producing increased fragmentation and specialisation within the scientific community, and the sub-division of existing scientific communities.

Kuhn comments that Fleck pointed out that: '[v]ery different thought styles are used for one and the same problem more often than are very closely related ones.'[153] And when people from different disciplines work together on the same problem, new

---

[151] Thus even scientists who explicitly state that they have religious beliefs separate them from their scientific practice (for example, John Polkinghorne (1994), *Science and Christian Belief.* London: Society for Promoting Christian Knowledge).
[152] Galison, op. cit., note 61.

disciplines and associated new theories may co-evolve. So, for example, both natural scientists and social scientists from various disciplines (history, philosophy and sociology) worked together to produce approaches to knowledge such as SSK, the Radical Science Movement, and social constructivism in general. They did not change orthodox history/philosophy of science, but instead contributed to the creation of a new field/discipline alongside it. In turn, I worked out my discomfort with allopathic medicine within the field of social constructivism, that is, not within allopathic medicine itself.

Another, similar kind of marginality is that of people at the edges of established practices or mainstream scientific communities. Again, since they are on the margins of established practice, such people may well not be fully committed to established theories, and are more likely to be open to alternative perspectives.[154] So, these people may produce and/or support challenges to existing theories.[155] Reflecting on my own experiences: allopathic medicine was a belief system which, when I began to question what I took as its limits, was still relatively new as a direct experience for me (although I had studied science throughout school, and had a medical family background). That is, I was "marginal" to allopathic medicine; I had not fully taken on its tacit assumptions, and perceived its inconsistencies too clearly to feel able to continue with them.[156]

A third kind of marginality is that of new members of a disciplinary community, who are still to be fully socialised into the community, and so have still to fully absorb the community's beliefs and the various elements of its disciplinary matrix. Such people have less invested in the established disciplinary matrix of the disciplinary community

---

[153] Kuhn, foreword to Fleck, op. cit., note 5: ix.

[154] On the other hand, it is, of course, also possible that they may conform out of a wish to be included in the mainstream.

[155] See for example Sharon Traweek's discussion of Japanese high-energy physicists and their relationship with the North American high-energy physics community (Traweek, op. cit., note 93).

[156] Conversely, my contemporaries, unlike me, did not perceive insurmountable contradictions between the theory and practice of allopathic medicine, and so continued within it, so becoming socialised as allopathic medical doctors. Such people do not challenge existing practices, until, for some reason, they come to recognise contradictions between claim and reality, theory and empirical results, and to perceive that anomalies are significant for existing theories.

and the theories which exist within it. They may therefore be more likely to perceive that inconsistencies (anomalies) between theoretical claims and experience or practice are significant.

Thus, marginal people may be key in developing new theories, particularly since it may be difficult to convert non-marginal people to a new theory. As I have noted, Kuhn claimed that, although new theories may result in debates and controversies, new theories *alone* are not enough for scientific revolutions. People's investment in existing theories can be so strong that it may be that most theories are only superseded through time passing, as people at the heart of existing disciplines, who have most invested in existing theories, are replaced by people who adhere less strongly to existing theories, or strongly support new ones.

The development of the theory of the social construction of knowledge is itself an example of this process. Although Fleck's ideas received little attention in 1935,[157] during the final few decades of the 20th century the argument that knowledge has a social component gained in currency, and Trenn et al point out that Fleck forecast:

> the emergence of a thought style compatible with his own theory of thought style and thought collective: "The thought style is a social product: it is formed within a collective as the result of social forces. This circumstance links problems of natural science with those of sociology and especially the sociology of thought, a science which unfortunately still remains grossly neglected, but is bound soon to move into the center of intellectual interest."[158]

New theories do not always result in scientific revolutions, however, nor even in full-blown controversies or debates over theory-choice, since scientists do not engage with every challenge to an accepted theory. For controversies to occur, a significant number of scientists, and/or influential members of the particular scientific community, must be

---

[157] Robert Merton's work ((1938; 1970), *Science, Technology and Society in Seventeenth-Century England.* New York and London: Harper and Row) met with similarly minimal response, whereas Karl Popper's *Logik der Forschung* (1935, translated as *The Logic of Scientific Discovery* (4th edition, 2002)). London: Routledge), contemporaneous with the work of Fleck and Merton, received far more attention (Trenn et al, preface to Fleck, op. cit., note 4: xvii).

converted to the new theory. So, for example, as Elaine Morgan points out, although there was plenty of evidence which potentially supported Alister Hardy's "Aquatic Ape" theory, this theory never reached the point of controversy but was simply ignored by other physical anthropologists.[159] Alternatively, people in scientific communities may adapt a new theory to fit the currently dominant theory.

In a paper in which he sets out to explain misunderstandings of and negative responses to the SP, David Bloor discusses what he calls "conventionalism," the process by which people selectively absorb or remember new ideas, shifting them in the direction of the culture of the person who is remembering them.[160] He argues that a group acting in this way will gradually come to share what he calls a "schema,"[161] and so certain patterns of thinking become norms which the group sustains in the course of its interactions. Elements of culture from one group are transformed as they are absorbed into the thinking of another.

Bloor argues that this does not mean that members of one group misread or misunderstand the other group, but that, since they respond from the range of interpretive resources they have at their disposal, they "conventionalise" the meaning in terms of the collectively held schema of their group and the meanings which function within it, thus adjusting new ideas to fit their dominant schema.[162] He claims that every group acts in this way to conventionalise its body of ideas, using them as a shared resource, and asserts that Kuhn's description of science as a paradigm-based activity illustrates how conventionalism has both positive and negative aspects (sustaining both truth *and* error),

---

[158] Trenn et al (preface to Fleck, op. cit., note 5: xviii), and endnote 3, citing Fleck, 'Zur Frage der Grundlagen der medizinischen Erkenntnis,' *Klinische Wochenschrift* 14 (1935): 1255-9, p 1259.
[159] Elaine Morgan (1985), *The Descent of Woman,* revised edition, London: Souvenir Press. Also Elaine Morgan (1997), *The Aquatic Ape Hypothesis*. London: Souvenir Press.
[160] David Bloor (1997), 'Remember the strong programme?' *Science, Technology and Human Values*, 22: 373-85: 375, drawing on Frederic C Bartlett (1932), *Remembering: A Study in Experimental and Social Psychology.* Cambridge: Cambridge University Press.
[161] The schema then becomes 'the base-line for the operation of the very process by which it was generated in the first place,' so generating 'a cognitive norm and a cognitive institution' (Bloor, op. cit., note 160: 377-8).
[162] Bloor, op. cit., note 160: 380.

and is a ubiquitous feature of all systems of belief.[163] A group sustains a paradigm by its cycle of behaviour, Bloor argues, which includes its pattern of reasoning.[164]

Bloor's schemata are very close to Kuhn's disciplinary matrices and his argument implies that people tend to absorb challenges to their schemata (such as new theories) *into* their schemata, conventionalising new ideas or elements of culture from other groups to fit the schema (disciplinary matrix) of their own group. Using the interpretive resources which people have at their disposal (which include their sets of values and metaphysical paradigms), they adjust the challenge, rather than their schema. That is, as Duhem stated, people tend to act to "save the theory," or, in terms of Kuhn's "normal science," people explain anomalies in terms of existing theory. This implies that people have to have a significant motive to take a new theory fully on board rather than "conventionalise" it.

IMPLICATIONS FOR MY STUDY

Kuhn's particular focus was scientific revolutions: how scientists come to replace existing scientific theories with new ones. In the main, I have suggested, such theory change tends to affect exemplars and symbolic generalisations within the disciplinary matrix of the particular scientific community, while leaving values and metaphysical models untouched. Scientists exchange one theory for another and return to "normal science," and they are able to do so relatively easily because the broader framework of scientific practice is largely untouched by this kind of theory change.[165] Nevertheless, theory change is unsettling.

---

[163] Bloor, op. cit., note 40: 6. See also Harding's argument that cultures are both toolboxes and prison houses for producing new knowledge (Harding, op. cit., note 79), and Foucault on power as both constructive and destructive (note 100 above).

[164] Bloor, op. cit, note 40: 7.

[165] See my discussion earlier in this chapter (p. 24) on Galison's metaphor of a stone wall for strength through intercalation and Wittgenstein's similar rope metaphor.

Kuhn argued that a new theory is incommensurable with that which it replaces and claimed that adequate translation and "good" (that is, scientifically acceptable) reasons are insufficient for converting someone from an existing theory to a new one. I suggest that this is because one of the things which is challenged when people change theories is their tacit beliefs. That is, for people to be converted to a new theory they have to change not only the intellectual statements/arguments with which they consciously engage, but also elements of their tacit knowledge, which link to their tacit, internalised beliefs.

The fundamental beliefs which people hold about the world seem to the people who hold them to be *how things are* (how the world is and which kinds of knowledges, beliefs and actions are valid), rather than *constructions* about how things are. People may not be aware that their beliefs are contingent, nor even aware of exactly what their beliefs are.[166] In turn, theories, which people accept in part because of their beliefs, do not seem contingent, but instead seem logical, rational and the truth.[167] As Kuhn pointed out, scientists are not explicitly taught their values and metaphysical models, but absorb them indirectly, and I suggest that this means that they are difficult to identify, address or challenge.

Thus, new theories are unsettling and destabilising on a deep, perhaps more emotional level,[168] and I suggest that this is part (consciously or unconsciously) of why people resist new theories. Although people claim to choose between theories on purely intellectual/rational grounds, theories are rooted in unexamined background assumptions, taken-for-granted beliefs and understandings, including values and

---

[166] As Mario Biagioli argues, someone's beliefs are the only ones they have (Biagioli, op. cit., note 77: 198).

[167] This is, of course, true for all of us, but perhaps less so for those who have actively examined their own beliefs, such as some ethnographers, or social constructivists who examine their own knowledge production in the "reflexive turn." See also Peter Ludwig Berger and Thomas Luckmann (1967), *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Harmondsworth: Penguin.

[168] And possibly also spiritually/existentially, since new theories can challenge scientists'/people's sense of meaning; see Mary Midgley (1992), *Science as Salvation: A Modern Myth and its Meaning*. London: Routledge; also see Kevin Sharpe (1984), *From Science to an Adequate Mythology*. Auckland, New Zealand: Interface Press.

metaphysical models, which are part not only of scientific or allopathic medical culture but also of "Western"/"Northern" culture more broadly.[169]

As Sandra Harding points out, culture-wide androcentric, eurocentric and bourgeois assumptions, such as those of the "West"/"North" are invisible to people within those cultures and from those backgrounds; they are embodied in the conceptual structures of the culture concerned.[170] Harding argues that the different interests of different groups mean that different groups may produce knowledge claims which are fundamentally incompatible, and I suggest that, in addition to different interests, different groups are likely to have different metaphysical models. So perhaps excluded knowledges always relate to different metaphysical models from those of dominant knowledges.[171]

The engaged social constructivist argument that if knowledge is a social product then all members of society should be involved in its production is particularly relevant in relation to Kuhn's metaphysical models. Metaphysical models such as what can be investigated is what exists contribute to how scientists identify what is worth scientific exploration and what is not, which relates to what the scientific method can examine and what it can't, and which, as I have suggested, is often effectively equated with what matters and what doesn't, which in turn leads to Harding's "systematic ignorance."

Values and metaphysical models are deeply held and often unquestioned, and are therefore less rational and more emotion-laden than other elements of the disciplinary

---

[169] Since, as I discussed earlier, science and "Western"/"Northern" culture are interlinked.

[170] Harding, op. cit., note 78: 135.

[171] So, for example, Patricia Hill Collins cites June Jordan's argument about the difficulty of moving between epistemologies (June Jordan (1985), *On Call: Political Essays.* Boston: South End Press: 130, cited in Collins, op. cit., note 80: 239), and Jordan's statement that it is impossible to translate instances of Standard English which focus on abstraction or nothing/nobody alive into Black English, since that would warp the latter into ideas which do not match its person-centred assumptions. That is, these two forms of English may share many items of vocabulary, but they (and hence the people who use them) do not share the metaphysical concept of abstraction. Thus too issues arise concerning the convention of using passive constructions in scientific language and writing (for analyses of scientific rhetoric see for example Michael Mulkay (1985), *The Word and the World: Explorations in the Form of Sociological Analysis*. London: Allen and Unwin and Jonathan Potter (1996), *Representing Reality: Discourse, Rhetoric and Social Construction.* London, Thousand Oaks and New Delhi: Sage).

matrix. So in relation to these elements of the disciplinary matrix the dichotomy between rational and emotional (which is critical for natural scientists' version of objectivity and for neutrality, both of which, as I have outlined, are key values for science) is blurred. In addition, since values and many metaphysical models are common to the disciplinary matrices of many disciplines they both link disciplines, and also contribute to maintaining those links and the broader framework of practices. Thus, although I accept the "disunity of science" claim that there is no single "science," but rather multiple, separate sciences, I suggest that it still makes sense to think of "science" or "allopathic medicine" in the singular in relation to those elements which are shared between multiple disciplinary matrices.

Although theory change touches on people's values and metaphysical models, however, these parts of disciplinary matrices are not usually significantly affected by theory change, since many perceptions of anomalies between existing theories and empirical findings revolve around small local inconsistencies, which therefore relate to exemplars and symbolic generalisations. Nevertheless, on occasion a new theory has wider consequences, which necessitate people's addressing the unexamined assumptions which underpin a scientific theory, or indeed the scientific method itself. So, for example, "new" or quantum physics and its claim of an "observer effect" or "action at a distance" potentially challenges not only the exemplars and symbolic generalisations of "old" physics, but also other elements of the disciplinary matrix, such as the values of detached objectivity and neutrality.[172]

That is, I suggest that some new theories have consequences for the values and metaphysical models of a community's disciplinary matrix. Since these elements of the disciplinary matrix are shared between disciplinary communities, these kinds of new

[172] For a discussion of the shift from Newtonian physics to relativity and quantum theory as an example of paradigm shift, see Martyn Hammersley (1990), *Reading Ethnographic Research: A Critical Guide.* London and New York: Longman: 11. For an example of another theory change, from the theory of phlogiston to that of oxygen, see Barnes and Bloor (op. cit., note 112: 33-4) citing JB Conant (1966), 'The overthrowing of phlogiston,' in JB Conant and KK Nash (eds), *Harvard Case Histories in Experimental Science*, vol. 1. Cambridge, MA: Harvard University Press.

theories potentially challenge not only the disciplinary matrix of the particular community of the people who produce those theories, but also challenge the disciplinary matrices of other disciplinary communities outwith the immediate disciplinary field within which the theory change has occurred.

As many studies of scientific controversies have shown, people struggle vigorously over theories which have consequences only for exemplars and/or for symbolic generalisations. I suggest that, since theories which implicitly or overtly challenge values and metaphysical models challenge the basis of science itself (by challenging elements of the disciplinary matrix which are both shared across disciplines, and also held tacitly by scientists), scientists' struggles over such theories will be even more vigorous, and will include scientists from a range of disciplines, who all have reasons to try to "save" values and metaphysical models.

Theory change with wide-reaching implications

It seems to me that both of the theories on which my study focuses – the theory that knowledge is socially constructed and the theory of total pain/care – have consequences for values and metaphysical models, and so both theories have implications for disciplinary matrices beyond those of their own immediate disciplinary fields. The theory that knowledge is socially constructed potentially redefines understandings of knowledge and the process of knowledge production in relation to the systematic production of knowledge (whether for allopathic medicine, natural science, or social science), while, as I will discuss later, the theory of total pain/care redefined the health care needs of dying people, and the associated responsibilities for health care professionals.

I have argued that the theory of social construction of knowledge can itself be analysed in Kuhn's terms,[173] and the various debates and struggles between theorists of

[173] See also Malcolm Ashmore's *Reflexive Thesis* – a reflexive analysis of SSK in SSK's own terms (op. cit., note 120).

knowledge around the various understandings and interpretations of Kuhn, SSK and the SP can be understood as part of the process of developing Kuhn's "normal science" in relation to this theory. Within these debates a key difference, it seems to me, is that between those theorists who perceive that the theory of social construction of knowledge leaves the values and metaphysical models of the wider disciplinary matrix of natural science untouched (thus, Bloor claims that SSK leaves science unaffected) and those who do not (who I have called engaged social constructivists).

SSK theorists tend to take an historical approach when exploring the factors involved in how theories become established, and how scientific communities judge them, and come to accept them, as true or false. By, in the main, examining resolved controversies, SSK/the SP predominantly addresses theory change in the past, asking how a particular group of people at a particular time came to believe a particular theory. Since this kind of study is removed in time, and not about the here and now, it can be contained and non-reflexive, and may seem to have no consequences for current scientific practice, including that of SSK itself.

However, as I have illustrated, reflexive and/or engaged social constructivists argue that the theory of the social construction of knowledge, which relates who people are to what they do (including their production of knowledge), has consequences for the theorist's *own* knowledge production, requiring the reflexive application of this theory to the theorist's own beliefs and actions. Engaged social constructivists actively engage with and challenge existing understandings of knowledge; unlike other social constructivists, they do more than demonstrate that these understandings are contingent.

By arguing that if interests (and beliefs) shape knowledge this is true for all knowledge – whenever, and by whomever, it is produced – engaged social constructivists therefore take on board the consequences for "science as usual" which, they argue, the theory of social construction implies. Perhaps this is the only point of agreement between engaged social constructivists and scientists who are opposed to social constructivism. Patricia Hill Collins points out that, while alternative knowledge

claims rarely threaten conventional knowledge, but are instead ignored, discredited, marginalized or absorbed ("conventionalised," in Bloor's terms), alternative *epistemologies* challenge the very basis on which those in power legitimate their knowledge claims:

> If the epistemology used to validate knowledge comes into question, then all prior knowledge claims validated under the dominant model become suspect.[174]

Engaged social constructivists explicitly challenge (and argue that the theory of social construction implicitly challenges) natural scientists' claim that science is value-neutral, together with another fundamental value which is shared between scientific communities: that of detached objectivity. This challenge has huge implications for the scientific method, and so for allopathic medical and natural science across all disciplines, and I suggest that this is why most natural (and many social) scientists react so strongly against the theory of social construction, such as in the so-called "science wars" between proponents of the social construction of knowledge and a significant number of practising (natural) scientists and orthodox/mainstream historians and philosophers of science.[175]

Although engaged social constructivists claim that science is value-laden, scientists do not consider their values to *be* values, but rather as essential, unquestionable givens, part of the "neutral" scientific method (the valorisation of which is itself, of course, an example of a value for science). Thus, as I have noted, scientists do not perceive their values (nor their metaphysical models) as contingent, but take these background, implicit, framing understandings (shared both with a scientist's immediate disciplinary community and also with the wider scientific community) as given or self-

---

[174] Collins, op. cit., note 80: 240-1. I would add that this is the case not only for prior knowledge claims, but also for those made in the present and in the future.

[175] For a well-publicised example of the "science wars," and of the vigorous, and at times offensive responses to science studies, see Paul R Gross, Norman Levitt and Martin W Lewis (1996) (eds.), *The Flight from Science and Reason.* New York: New York Academy of Sciences. See also Lewis Wolpert (1992), *The Unnatural Nature of Science.* London: Faber and Faber.

evident. It is therefore very unsettling when these understandings are questioned, because social constructivist analyses threaten scientists' deeply held beliefs – which seem to scientists to be how the world is, not *theories* about how the world is.[176]

I can understand why people who have never questioned the tacit assumptions of science, technology and/or allopathic medicine would have great difficulty with social constructivism, since, as I will discuss in the following section, even though I felt uncomfortable with allopathic medicine, and found science studies appealing, I nevertheless experienced difficulty with the implications of the theory of social constructivism for (scientific) knowledge, and found it very hard fully to take on board the argument that scientific knowledge is contingent.

"Going native": taking on board fundamentally challenging theories

Kuhn stated that good reasons are insufficient for accepting a new theory, since an individual may be intellectually convinced by a new theory but unable to internalise its implications. As I noted earlier, he argued that, to make a new theory one's own, 'one must go native,' that is, begin to think and work in the new language. However, as Fleck commented, transformation from one thought style to another may not be rapid but may involve a slow process of change or differentiation.

That is, while a new theory may make intellectual sense to a person, and so their initial acceptance of it may be rapid, they may (in part for the reasons I have outlined above) find it harder to implement the theory in practice. People's initial conversion to a new theory (or, in Argyris and Schön's terms, their "espousal" of the theory[177]) may be quick, but they may be much slower in absorbing the implications (consequences) of this change, and may need to spend time thinking and working through the issues which arise

[176] As an example of the extreme annoyance relating to this discomfort, I am particularly thinking of the frequent participation of Lewis Wolpert (Professor of Biology as Applied to Medicine at UCL) in Radio 4 discussion programmes such as 'In Our Time' and 'Start the Week,' and his impassioned attacks on social constructivism and social constructivists.

[177] Argyris and Schön, op. cit., note 6.

from the new theory.[178] That is, it may take time before they are able to practise "normal" science in relation to the new theory, or, in Argyris and Schön's terms, to move from an "espoused theory" to a "theory-in-use."[179]

Thus, while an individual cannot *choose* to accept a new theory, since s/he may find her/himself unable to internalise it, even someone who has accepted a new theory "in theory" may not, initially, be able to fully express it in practice. This is the case for any new theory, and I suggest that it is even more so if the new theory challenges much of the disciplinary matrix of a disciplinary community. It is possible, however, that *because* values and metaphysical models are so much part of the framing context of practice, the implications of a new theory for them may be largely ignored. Thus, even scientists who nominally accept a new theory, although they may pay lip service to its (implied) consequences, may continue to practice science as usual outwith the immediate environment where the new theory is directly used. That is, people may nominally accept a new theory, yet conventionalise elements of it.[180]

As an example of the difficulty with fully taking on board profoundly challenging new theories, I noted earlier in this chapter that I experienced a very powerful initial sense of connection and recognition when I first discovered the field of science studies. This way of thinking about science, technology and (allopathic) medicine made sense to me; SSK offered me a theory and a way of thinking about my discomfort with allopathic medicine. However, in the longer term I have had to struggle with the implications of this theory, both for science, technology and allopathic medicine and for my own production of knowledge. That is, my initial "conversion experience" was followed by my (lengthy, and ongoing) working through and working out the consequences of the theory of social construction of knowledge.

---

[178] Again, this may parallel the spiritual conversion experiences from which Kuhn drew the metaphor.
[179] Ibid.
[180] See for example Hacking's argument that for scientists old theories still hold for data which are entirely contained within the original domains of the old theory (Hacking, op. cit., note 56).

With hindsight, my discomfort with allopathic medicine related to my perceptions of insurmountable difficulties with its underpinning assumptions, values and metaphysical models; contradictions between its claims, theory and practice, and people's experiences of health, ill health and health care. I consequently found myself asking questions which (although at that time I did not, and could not, frame them in this way) were addressing fundamental issues such as: What is allopathic medicine for? Why is it like it is? What is it trying to do? What is the underlying understanding of ill health/disease, and, therefore, of health/cure with which allopathic medical practitioners are working? Is this the only way of thinking about and enacting health and health care?

Nevertheless, despite this (and its later echo in my discomfort with the taken-for-granted assumptions underpinning IT), and despite the deep resonance which the theory of the social construction of knowledge had for me, it was still hard for me fully to take on board the implications of the argument that scientific and allopathic medical knowledges are contingent.

In parallel to the claims that natural science's explanations of the natural world are the only possible ones, stemming from a direct insight into nature, and that they are not *theories about* nature but describe *how nature is*, and other ways of thinking are wrong and/or misguided, so too allopathic medicine claims that its explanations of ill health are the only possible ones, that they stem from a direct insight into nature, that they are not *theories about* the human body but describe *how the human body is*, and other ways of thinking are wrong and/or misguided.

I had been educated in this system of thought, and, despite my discomfort with it, I still found what Harding calls the "internalist epistemology" (that is, that there is one nature, one truth about nature, and one science which reveals that truth) extremely powerful. Powerful, and also seductive, because, as I noted above, this approach to knowledge provides one with a sense of certainty, the sense that all problems have answers, which can be determined scientifically, even if they have not as yet been identified. The alternative to this, accepting that scientific truth is contingent and

temporary, implies embracing uncertainty and its consequent insecurity.

I think that the appeal of the promise of scientific certainty is not restricted to natural scientists,[181] and the investigator of current scientific practice, even if s/he has not been trained in natural science, may already share much of the culture of the practitioners (including the valorisation of the scientific method). It therefore requires an effort for the investigator to maintain a distance and not "go native," taking on the unexamined assumptions and framing beliefs of the scientific community under investigation, and so producing internalist analyses.

Arguably, it is easier to identify culturally specific features of events or groups which are historically or culturally distant, and perhaps the distance of SSK-type historical studies from the associated culture makes it easier for the investigator to reveal scientists' unexamined assumptions, which are also removed from her/his own. It is much harder to get the necessary distance to identify these as one gets closer to home, but it is not impossible to explore current practices and also situate them more widely, paying attention to their social, political, economic and historical context. However, this requires a conscious self-consciousness on the part of the investigator, who needs to constantly ask her/himself how s/he would describe this belief/behaviour to someone from another culture.[182]

---

[181] As I have already noted, science and Western/Northern culture are intimately linked.

[182] Although see the debates in anthropology over studying "at home," and on the other hand anthropologists who "go native," taking on the beliefs of the culture which they are studying (see also Byron J Good (1994), *Medicine, Rationality and Experience: An Anthropological Perspective.* Cambridge: Cambridge University Press: 89, and Stanley J Tambiah (1990), *Magic, Science, Religion and the Scope of Rationality.* Cambridge: Cambridge University Press on the question of translatability in anthropology). An ethnomethodological perspective such as that of Lynch, which I briefly discussed above, is interesting for social constructivist studies, especially in relation to studies of practice, since, as I will outline when I discuss my methodology in the next chapter, there are some ways in which social constructivist studies are (or can be) similar to what anthropology does, and, as I shall discuss, medical anthropology has grown as a field in recent years, linking also to science and technology studies (STS), see for example the work of John Law ((1991) (ed.), *Power, Technology and the Modern World.* Oxford: Blackwell). Both fields ask what meanings people ascribe to events, activities and objects, and what meanings underpin people's behaviour. Both fields seek to make explicit the implicit (tacit) assumptions which people hold; they unsettle the taken-for-granted, make the familiar strange, and the strange familiar.

Some scholars of science as practice have not managed to maintain this distance. Bruno Latour, in his work both alone and in collaboration with Michel Callon has been criticised for "going native" by taking on scientists' understandings of the natural world.[183] So, too, Ian Hacking, in his studies of what he calls the "self-vindication" of "stable sciences" deliberately does not include those items which he says scientists do not literally use in their experiments: the worldviews and visions of how the world is which they use to direct their research, their expectations about what the world is like and their styles of scientific reasoning which govern their theories and their interpretations of data.[184] He states that he is not interested in exploring these underlying aspects of culture, although he notes that both his theory of self-vindication and his theory of self-authentication of styles of reasoning are circular (that is, internalist),[185] and remarks that the move to microanalyses of practice have left these 'big underlying aspects of culture hanging' and that they need more examination.[186]

I suggest that by disregarding these factors, Hacking is doing what scientists themselves do. That is, by choosing not to investigate a scientific community's wider beliefs, but to take them as given, part of the background against or within which science is practised, Hacking, like natural scientists, separates what Harding calls the "context of discovery" from the "context of justification."[187]

---

[183] Bloor claims that Latour has taken on the perceptions of scientists, rather than studying those perceptions, pointing out that Latour gives agency to inanimate objects, characterising their resistance as agency, and that this is very close to scientists' claims that science must be "the truth" because scientists are unable to make the natural world do what they want (Bloor, op. cit., note 40). In contrast, SSK holds that constraints of nature are a given; what SSK seeks to explain is why people choose different theories to explain nature (and nature's not doing what people want or expect). Similarly, Collins and Yearley criticise what they perceive as Michel Callon's unproblematic reproduction of scientists' characterisations of natural world, arguing that Callon has unquestioningly accepted the tales about the natural world which scientists told him (Collins and Yearley, op. cit., note 120).

[184] Hacking, op. cit., note 56: 33; 51.

[185] Hacking, op. cit., note 56: 51, footnote 2.

[186] Likewise, Andrew Pickering, despite arguing that social factors shape how scientific communities decide on solutions to scientific problems, specifically says that he is not exploring grand, all-encompassing world views (as he says the term "culture" implies), despite noting that 'unifying characterizations of entire cultures might also be perspicuous on occasions' (Pickering, op. cit., note 64: 3, footnote 1).

[187] See discussion of Harding (1991) (Harding, op. cit., note 114), p. 40 above.

I suggest that in this way this kind of internalist focus on scientific practice separates science from its wider social context, and, by ignoring this, runs the risk of the investigator taking on the belief of scientists that their theories about the world describe how the world is. This kind of analysis is then closer to orthodox history or philosophy of science[188] than to the theory of social construction.

Again, reflecting on my own experience as a student of allopathic medicine and IT, I know how I oscillated between the "what for?" question and the fascination of these purely factual subjects, and the seduction of the associated (apparent) certainty and the security of explanations. Without stepping back from practice to explore the implicit sets of understandings with which practitioners are working, if one limits oneself to focusing on practice alone, it is easy to lose sight of the contingency of practice, and so current practice can appear the only way of doing things.

These issues were key for me in relation to my study. Although feminist research methods, linking to the issues of knowledge which I have discussed above, hold that detachment and objectivity are illusions, which raise political issues, and although I accept this to some extent, I would argue that, even if one accepts that one is inevitably involved and not separate from the situation one is studying, it is still possible, and, I would argue, necessary, to maintain a tension between being detached and engaged, a kind of detached engagement (or situated objectivity).[189] So, as I will discuss in the next chapter, although hospice philosophy appealed to me, I aimed to maintain a degree of distance as an observer, and to never be fully or solely a participant. I set out to study the hospice as an outsider, not taking on board the culture entirely, but instead seeking to explicitly examine the taken-for-granted assumptions which framed practice: the beliefs and understandings of health care, death and dying which workers in the hospice had, and how these beliefs and understandings related to workers' practices and, if at all, to Saunders' theory of total pain/care.

---

[188] Which, in Bloor's terms, is a history of truth and error, including the gradual correction of error.
[189] I discuss this further in the next chapter.

"Total pain/care"

Cicely (now Dame Cicely) Saunders developed her theory of total pain/care outwith allopathic medicine, having been a nurse and subsequently a medical almoner,[190] in which role she had a significant relationship with a dying patient.[191] Following his death, she began working as a volunteer sister at St Luke's Home for the Dying Poor in Bayswater, where she saw the regular giving of drugs for pain relief,[192] and had further significant relationships with other people who were dying. On the basis of these experiences, she determined to challenge existing allopathic medical care for dying people, and deliberately moved into the allopathic medical community in order to acquire the necessary status to influence it. She trained as an allopathic medical doctor in her 30s, and in 1958, as a newly qualified doctor, she began a research scholarship into pain in the terminally ill, working at St Joseph's Hospice, Hackney, where she introduced the regular giving of drugs, gradually introducing the use of morphine mixture and heroin.[193]

Through her various experiences (which also included a spiritual conversion experience),[194] and drawing on the long-established religious tradition of hospices, Saunders developed her theory of "total pain" and "total care," which holds that the pain of people who are dying has multiple aspects, not only physical but also social, emotional, psychological and spiritual, and that these aspects are interwoven. She argued that dying people should therefore receive "total care," that is, care which addressed all these aspects of pain.[195]

---

[190] Previous name for medical social worker.
[191] Shirley du Boulay (1984), *Cicely Saunders: The Founder of the Modern Hospice Movement*. London: Hodder and Stoughton: 54-8.
[192] du Boulay, op. cit., note 191: 61-2.
[193] du Boulay, op. cit., note 191: 68-70.
[194] Note that Kuhn used this term by analogy with the more generally understood meaning of the term conversion, that is, associated with a spiritual or religious event, but Saunders' own conversion experience was indeed spiritual, and later had implications for allopathic medical knowledge, offering the potential for conversion in Kuhn's analogous sense.
[195] Saunders focused on pain because in the 1950s intractable pain was a major issue for people dying with cancer, and one which challenged professional carers. She has been criticised for her use of the word

This was an explicitly different approach to the allopathic medical care of dying people, and it was incommensurable with previous allopathic medical theories of pain, which separated physical pain from other aspects of a person, and treated it accordingly (that is, purely on a physical basis). Even Melzack and Wall's "gate theory" of pain, which claimed that emotions have a role in pain, and so contributed to the acceptance of a more holistic approach to pain management, explained the role of the emotions in physical terms, that is, in terms of the physical, neurological effect of emotion on pain perception.[196]

By the end of 1959 Saunders had involved a group of people in London in her project to found St Christopher's Hospice, the first modern hospice (an explicitly religious (although non-denominational) organisation), which was established in 1967. In parallel with this, she continued with her work on pain relief, conducting randomised controlled trials on opiates, in order to support her case for giving opiates for pain relief on a regular basis rather than on demand (and so, incidentally and ironically, contributing to the physical emphasis of allopathic medicine). She was able to conduct such studies because new drugs for the relief of pain began to be developed during the 1960s, including opioids from the 1970s onwards.[197]

The development of these drugs increased the capacity of allopathic medicine to relieve cancer pain, and so allopathic medical professionals were enabled to intervene in

---

"pain," but by using the word pain she sought to stimulate awareness that the distress of a dying person had many facets, not only physical, so that a dying person needed not only drugs but also human understanding and practical help. However, since she developed her theory, the allopathic medical profession's increased ability, owing to pharmacological developments, to address pain, plus other developments (such as new chemotherapeutic drugs) mean that people now live longer with disease which allopathic medicine defines as incurable, and have additional symptoms to pain, such as fatigue or breathlessness. "Total distress" or "total need" might therefore be better terms than "total pain" (although each of these terms has its own drawbacks). Regardless of the term, however, the central point of Saunders' philosophy still applies: that the needs of dying people are interwoven and that carers should respond accordingly, by providing "total care."

[196] Melzack and Wall argued that neural pathways were involved in the perception of pain, via descending pathways from the cortex of the brain, and in this way emotions (expressed or experienced in the cortex) were important for pain. (Ronald Melzack and Patrick D Wall (1982), *The Challenge of Pain.* Harmondsworth: Penguin).

the care of dying people rather than standing by. The possibility of allopathic medical intervention was a key factor in what is sometimes called the medicalisation of hospice,[198] and there are now hundreds of hospices in Britain and internationally. From 1967 onwards modern hospices began to be set up in England, and the first Scottish hospice was established in 1978. "Palliative care" developed out of this movement,[199] and in 1987, palliative care became a medical speciality, with medical students now spending part of their training in hospices or in hospital palliative care teams or departments.

Saunders' approach to the care of dying people implied a radically different perspective on pain and ill health (and also, therefore, on the care which dying people required) from that which was (and is) dominant in allopathic medicine. I noted above that two of the metaphysical models which underlie the allopathic medical model hold that mind, body and spirit are separate and separable, and that ill health or disease has physical causes. Allopathic medical practitioners respond accordingly: by providing physical solutions which aim to attack disease-causing agents or to destroy tissue defined as unhealthy (such as tumours). Thus, allopathic medical practitioners generally perceive their role as facilitating or performing physical interventions, although they may recognise that people have additional needs, and may therefore refer the people for whom they are caring to other professionals for non-physical care. Saunders' "total pain," however, integrates mind, body and spirit, and her "total care" explicitly includes the emotional, psychological and spiritual dimensions as *part* of allopathic medical care,

---

[197] Ashley Grossman (1988), 'Opioid peptides and pain,' in Mann, RD (ed.), *History of the Management of Pain*. Carnforth, Lancs: Parthenon: 131.

[198] See for example Nicky James and David Field (1992), 'The routinization of hospice: charisma and bureaucratisation,' *Social Science and Medicine*, 34 (12): 1363-75.

[199] Thus hospices are now identified as organisations which provide specialist palliative care for people approaching the end of their lives (The National Council for Hospice and Specialist Palliative Care Services (2003), 'Information sheet on palliative care and hospices,' London: National Council for Hospice and Specialist Palliative Care Services; also held on http://www.doh.gov.uk/cancer/palliative-informationsheet.pdf. Also see the mission statement of St Christopher's hospice: 'St Christopher's exists to promote and provide skilled and compassionate palliative care of the highest quality,' www.stchristophers.org.uk).

and I suggest that this theory thus implies a different metaphysical model to that of most of allopathic medicine.

In relation to my above discussion of how theory change occurs, I suggest that Saunders' experiences, both personally and professionally, in a range of roles in a range of situations, placed her on a boundary between various health care disciplines. This, together with her position as an outsider (a "marginal woman" (to adapt Fleck's phrase): a Christian doctor, who explicitly integrated spiritual and medical concerns,[200] who had been trained in disciplines other than allopathic medicine, and who was significantly older than the average medical student when she came to study medicine), enabled her to perceive anomalies in allopathic medical theory and practice. She then explicitly set out to create an example of alternative practice, to create a new field rather than working within established fields, saying: "We moved out so that attitudes and knowledge could move back in."[201]

I think that there are therefore parallels between engaged social constructivism and Saunders' theory of total pain/care. Engaged social constructivism explicitly challenges the values and metaphysical models of science. Similarly, the theory of total pain/care potentially or implicitly challenges the values and metaphysical models of allopathic medical science. In addition, both engaged social constructivism and the modern hospice movement follow similar paths in seeking to reclaim excluded knowledges or facets of knowledge, interweave them with established forms of knowledge, and then implement this new knowledge in practice. Further, Saunders' argument concerning the total pain of dying people and their consequent need for total care interweaves the personal, the emotional and the intellectual, an approach for which engaged social constructivists argue, and which I am attempting in this study.

I therefore find an appealing symmetry between my approach to my study and the subject/object of that study: using an approach (engaged social constructivism) which

---

[200] du Boulay, op. cit., note 213: 95.

seeks to re-integrate excluded knowledges (such as those relating to the spiritual), to study a place (hospice) where, it is claimed, workers deliver care on the basis of a theory (total pain/care) which holds that care should address all the interwoven aspects of a person's needs (including the spiritual).

I am particularly interested in how theories which seek to change established practices are implemented in practice. I was therefore interested in both the relationship between the beliefs and practices (in particular the spiritual beliefs and practices) of workers in a particular hospice and the theory of total pain/care (and the insight which the theory of the social construction of knowledge might provide into this), and also the implications of the theory of the social construction of knowledge both for my research practice and my own production of knowledge in this thesis.

I have argued that the key differences between the allopathic medical mainstream and the theory of "total pain/care" relate to the spiritual dimensions of pain and care. The growth of the modern hospice movement and of the associated specialty of palliative care might seem to suggest that the theory of total pain/care has become accepted by, and so part of "normal science" for, at least part of allopathic medicine. My initial/framing research question was: since scientific (including allopathic medical) knowledge was constructed to exclude, and by excluding, spirituality, what does it mean to include a theory which explicitly includes spirituality in allopathic medicine, since by its inclusion of the spiritual, the theory of total pain/care challenges the values and metaphysical models of allopathic medicine. I also asked what was the relationship (if any) between the theory of total pain/care and practice in a particular hospice, and whether practices in that hospice also challenged the values and metaphysical models of allopathic medicine.

Thus, I set out to explore the spiritual aspects of hospice care. This might seem a contradictory starting point, because "holistic" or "total care" implies a seamless whole, which suggests that it is not possible to identify and/or separate the spiritual parts of this

[201] Cicely Saunders (1981), 'The founding philosophy,' p. 4 in Saunders, C, Summers, DH and N Teller (eds.), *Hospice: The Living Idea.* London: Edward Arnold.

care. Nevertheless, although it might not be possible to *separate* these elements of care, I felt that it would be possible to focus particularly on them, as a particular aspect of the care provided by workers in a particular hospice.

So in my fieldwork I aimed to explore the relationship between hospice workers' interactions with patients and hospice philosophy. I was trying to investigate the context of and the assumptions underpinning hospice workers' practices; asking what hospice workers believed about the needs of dying people and how this related to their practices. That is, I was asking who were the people who worked in that community, what were their knowledges, beliefs and practices, and which of these did they share? Could this hospice be conceptualised as a "thought collective" or as a "boundary zone" between different disciplines? What was the relationship between hospice workers and established systems of knowledge/practice? With what understandings of health, illness, death and dying were people in that community working? How did these understandings map to the theory of total pain/care? How did they relate to workers' practices?

CONCLUSION

In this chapter I have traced my movement through various understandings of the theory of social construction and how that led to this thesis, beginning by discussing how I came to science studies, and the views and understandings of that field with which I embarked upon my research, and which I presented in my proposal. In this part of the chapter I focused especially on those areas which at the outset of my study seemed likely to be particularly relevant to my fieldwork practice and/or findings.

However, as I have outlined, part of my movement through the theory of social construction, which included my fieldwork and my reflections on my findings, involved changes in my perceptions of which perspectives on the social construction of knowledge were relevant to my work. Thus, although this chapter precedes my methodological and empirical chapters, I did not begin my fieldwork with the detailed

understanding of Kuhn's disciplinary matrix which I have outlined, but developed it through and subsequent to doing and writing about my fieldwork.

I am more interested in how people implement new theories in practice than in how they come to accept them in the first place. Thus, I was more interested in exploring the relationship between current practices and the theory of total pain/care than in tracing the development of this theory and the process of how it became (apparently) widely accepted (or perhaps absorbed) by allopathic medicine.[202] My interest in the relation between theories and practices led to my initial exploration of the field of science as practice. Studies of science as practice also link to the concerns of medical anthropology, and so linked to my methodology. Nevertheless, I did not find the literature from the field of science as practice particularly useful in relation to my fieldwork findings.

I also began this study from a position of being sympathetic with engaged social constructivism, as argued for by feminist and/or postcolonial theorists. Like these theorists, I am uncomfortable with the self-limiting character of studies of knowledge production which adopt a detached, apolitical stance and do not investigate the wider socio-economic, political context. I think the engaged social constructivist perspective facilitates studies of knowledge which tend to be excluded and/or devalued by association with "women's work" and/or with the negatively loaded sides of powerful Western dichotomies between nature-culture, emotion-rationality and so on, for example spiritual, emotional and experiential knowledge. I therefore felt that there was a symmetry between this approach and the theory of total pain/care, and it was also a position which was relevant in relation to my interest in the implications of the social construction of knowledge for my own production of knowledge.

However, as I have briefly discussed above, and will consider in more detail in the following chapters, I found that the relationship between workers' practices and their espoused beliefs was not straightforward. Issues relating to implementing theories in

[202] Although this latter would be an interesting (historical) SSK-type study.

practice also arose in relation to my own research practice. While writing up my findings from my fieldwork, therefore, I returned to Kuhn and re-read his work. In relation to my empirical findings I found his concept of the "disciplinary matrix" helpful for thinking about theory change and its implications for practice, both generally, and specifically in relation to particularly challenging theories such as the theory of the social construction of knowledge and the theory of total pain/care.

Kuhn's disciplinary matrix is the intellectual context within which scientists produce and work with theories, and it has four elements: exemplars, symbolic generalisations, values, and metaphysical models. New theories are incommensurable with existing theories, and this means that to accept a new theory people have to reject elements of the disciplinary matrix which they previously accepted. Thus, people who adhere to different theories may use the same language, but perceive the situations differently, and so Kuhn also stated that translation is necessary between new and existing theories. However, he argued, translation and good reasons are insufficient for conversion to a new theory; for conversion, people must "go native," that is, internalise the theory, which is something they cannot *choose* to do.

Theory change usually affects exemplars and symbolic generalisations, but not values and metaphysical models. However, some new theories, such as the theory of social construction of knowledge itself and the theory of total pain/care, do have consequences for values and metaphysical models and, since these are shared between disciplinary communities, these theories have wider consequences for disciplinary matrices, not only of the scientific or allopathic medical discipline within which they are produced, but also of the wider scientific or allopathic medical community.

That is, the field of the social construction of knowledge itself can be considered as an example of a new theory, which does not only have consequences within its own disciplinary field (or fields), but also challenges elements of the disciplinary matrices of other disciplines. Thus, the social construction of knowledge is incommensurable with the approaches to and sets of understandings of scientific, technological and allopathic

medical knowledge of both conventional history and philosophy of science, and of many practising scientists. Similarly, the theory of total pain/care is incommensurable with some fundamental understandings (such as metaphysical models) across allopathic medical disciplines.

All theory change is associated with struggles and controversies, and I have argued that these will be intensified if the new theory affects values and metaphysical models. Further, even after controversies have been resolved and new theories been accepted, it takes time for people to work theories through in practice, and again this is even more the case for theories which affect values and metaphysical models, which people have internalised through their socialisation into a particular discipline. In addition, Bloor argues that people tend to conventionalise new theories in terms of their existing understandings or schema, and this may be particularly the case when new theories challenge fundamental elements of those existing understandings.

These points became key for me in understanding my fieldwork findings, but before I discuss this I will now move to the next chapter, where I will discuss my approach to methodology and analysis, and the links between this and the theoretical perspective I have outlined in this chapter. In the two subsequent chapters I will discuss my perceptions of practices in the hospice, first generally, and then focusing particularly on the spiritual aspects of those practices. Following these two chapters is a discussion chapter in which I will return to the themes which I have outlined in this chapter, and reflect further on the relationship between theories and practices.

- 3 -

METHODOLOGY AND ANALYSIS

INTRODUCTION

In this chapter I will discuss my methodological and analytical approach to my fieldwork. It is important to note at the outset that I conducted my fieldwork at a time when significant upheaval and transformation were taking place in "St Z's." Clearly, this must have had consequences for my findings, such that they would have been different at another time. It is, however, impossible to say in what way they would have been different. Further, this particular situation of evident change merely highlights the fact that an ethnography is always and unavoidably a historical document, which relates to a particular group of people in a particular situation at a particular time. As Michael Agar remarks, ethnography is an interaction between the people in the research site, the ethnographer, and the audience for the ethnographer's research findings.[1] Thus, as Agar comments, repeated studies of the "same" site often produce different findings, even when conducted by the "same" ethnographer. That is, the ethnographer who returns to the site where s/he conducted the first study is not the same person as the person who conducted that study, having changed, not least as a result of having conducted the first study. Likewise, the people in the research site will have changed over time, as too will the audience.

This chapter broadly falls into two parts; in the first I discuss the doing of my fieldwork and in the second I move on to consider issues for thinking and writing about it. This separation of data collection from data analysis is an artefact – particularly so in relation to ethnography, which entails an interaction between data collection and data analysis – but is convenient for organisational purposes. So, I begin the first part of the chapter by discussing the ethnographic method, and move on to consider issues such as gaining access to St Z's and where in St Z's I conducted my fieldwork. Various points

in this part of the chapter, therefore, connect to issues which I address in more detail when I discuss findings from my fieldwork in the two chapters which follow this one. Thus, I do not elaborate on these points in this chapter, but they will return later in my thesis, and I will indicate when this is the case.

I end the first part of the chapter with a discussion of how I recorded data from my fieldwork and a consideration of issues around leaving "the field." In the second part of the chapter, I discuss issues relating to analysis and to writing-up ethnography, considering some of the issues which arise to do with language, such as the use of pseudonyms, and I end by discussing my use of discourse analysis for analysing data from my interviews.

BEING THERE AND DOING MY FIELDWORK

Why ethnography?

I chose to use ethnography (that is, participant observation and ethnographic interviews) as my methodology for several reasons. First, because, as I have discussed in the previous chapter, I was particularly interested in exploring the relation between theories, beliefs, knowledges and practices, and, following the distinction which Chris Argyris and Donald Schön[2] make between "espoused theories" or "theories-of-action" (what people say that they do or aim to do) and "theories-in-use" (what people do in practice), I wanted to look at workers' (and patients') activities rather than (only) discuss them in interviews. Second, I thought that people might find the spiritual aspects of care difficult to talk about. Third, I felt that these aspects of care would be quintessentially interactive, and might therefore prove difficult to observe, so that it would be necessary to participate in such care, or at least attempt to do so, in order to begin to understand it.

The issue of the relationship between knowledge and practice, and Argyris and Schön's distinction between espoused theories and theories-in-use, could of course apply

[1] Michael Agar (1986), *Speaking of Ethnography.* Beverley Hills, London, New Delhi: Sage: 14-15; 19.

to any area of research, not only, nor specifically, to a study of spiritual aspects of care. However, in relation to this particular area, I feel that my fieldwork experience reinforced that this methodology was the right choice.

There are also links between contemporary ethnography and my theoretical, framing interests. Ethnography is increasingly concerned with knowledge and the knower. In the 1980s, what became known as the "writing culture" debate emerged in anthropology, revolving around two books in particular: *Writing Culture: The Poetics and Politics of Ethnography*[3] and *Anthropology as Cultural Critique*.[4] As James, Hockey and Dawson point out, these texts highlighted and responded to an epistemological and political crisis in anthropology, and the move by anthropologists, associated with an increasing sense of the unequal power relations which were inherent in the "objectivity" of traditional anthropology, towards thinking of, and exploring, anthropology itself as institutionally, historically and politically situated.[5]

This movement in anthropology and its focus on "the inextricable relationship between epistemology, politics and practice"[6] resonates with claims made by those studies of science which I discussed in the previous chapter. Similar questions are asked of anthropology as are asked of scientific, technological and medical knowledge: who, what, how and why anthropologists represent; the relationship between theoretical debates about representation and the practice of anthropology and of anthropologists; the implicit theoretical politics which shape any kind of anthropological practice.[7] So, as

---

[2] Chris Argyris and Donald A Schön (1974), *Theory in Practice*. San Francisco: Jossey-Bass. Also see Irwin Deutscher (1973), *What We Say/What We Do: Sentiments and Acts*. Glenview, IL: Scott Foresman.
[3] James Clifford and George E Marcus (eds.) (1986), *Writing Culture: The Poetics and Politics of Ethnography*. Berkeley: University of California Press.
[4] George E Marcus and Michael MJ Fischer (1986) *Anthropology as Cultural Critique: An Experimental Moment in the Human Sciences*. Chicago: University of Chicago Press.
[5] Allison James, Jenny Hockey and Andrew Dawson (1997), 'Introduction: the road from Santa Fe,' pp. 1-28 in James, A, Hockey, J and A Dawson (eds.) *After Writing Culture: Epistemology and Praxis in Contemporary Anthropology*. London and New York: Routledge.
[6] James et al., op. cit., note 5: 2.
[7] James et al., op. cit., note 5.

Henrietta Moore indicates, fundamental questions for anthropology are: "whose knowledge; what sort of knowledge; what constitutes the social?"[8]

Thus, as I noted in the previous chapter, questions about knowledge are current in anthropology as in social studies of STM, and so too are concerns about reflexivity. Doing social studies of STM reflexively means the researcher asks similar questions about her/himself as s/he asks about the people s/he studies. As Elizabeth Young and Raymond Lee point out, reflexivity implies and includes an understanding of the emotional implications of one's methodological preferences and the interaction and conflict between them and one's emotional responses. Young and Lee contrast this with the historically detached orientation of ethnographers, such as those from the "Chicago school," arguing that this detached orientation concealed a range of emotional responses.[9] Further, as I discussed in the previous chapter, detachment is itself an emotional position.

Doing ethnography

There is some debate over how many, if indeed any, "how-to-do-fieldwork" texts and courses exist. In 1980, Michael Agar stated that there was a significant amount of literature which addressed the "how-to-do" question, but that the literature was scattered throughout journals and had not been systematically reviewed.[10] However, 10 years later, Nancy Howell claimed that there was a dearth of such texts and courses, [11] and Jean Jackson commented that anthropology graduate school could be thought of as a kind of

[8] Henrietta Moore (1996), *The Future of Anthropological Knowledge.* London: Routledge.
[9] Elizabeth H Young and Raymond M Lee (1996), 'Fieldworker feelings as data,' pp. 97-113 in James, V and Gabe, J (eds.), *Health and the Sociology of Emotions.* Oxford and Cambridge, MA: Blackwell: 111.
[10] Michael Agar (1980), *The Professional Stranger: An Informal Introduction to Ethnography.* New York and London: Academic Press.
[11] Nancy Howell (1990), *Surviving Fieldwork: A Report of the Advisory Panel on Health and Safety in Fieldwork, American Anthropological Association.* Washington, DC: American Anthropological Association: 6-8; 189-90.

apprenticeship, and fieldwork as a kind of initiation rite.[12] Jackson claims that part of the "hidden curriculum" of graduate training in anthropology is the promotion of a mystique about the ethnographic enterprise, which includes adopting a kind of "sink-or-swim" approach to doing fieldwork, that is, making students "learn-by-doing," rather than teaching them how to do fieldwork.[13]

In my case, I took a course in ethnographic methods in the first year of study for my PhD, but this course did not address the practicalities of doing ethnography, focusing instead on theoretical issues, such as the aims and meaning of doing ethnographic fieldwork. Issues such as subjectivity and reflexivity in ethnography were much discussed (reflecting the existence of the many texts which consider these issues and discuss the writing up of fieldwork), but there was little discussion of fieldwork techniques as such.

One of the few "how-to" texts to which I was directed was the much cited work of James Spradley,[14] who explicitly set out to systematise participant observation through his Developmental Research Sequence (DRS) Method. I found his systematic approach (including his strategies for avoiding becoming swamped in data) reassuring at the outset of my fieldwork, and used his DRS Method as a framework for thinking about how to organise and manage my ethnographic data. Thus, as I will show in the following sections of this chapter, my fieldwork was basically modelled along the lines of Spradley's DRS Method.

Ethnography is a kind of 'exploratory inquiry,'[15] which can take different forms depending on the interests and approach of the ethnographer. Dell Hymes identifies

---

[12] Jean Jackson (1990), '"I am a fieldnote": fieldnotes as a symbol of professional identity,' pp. 3-34 in Sanjek, R (ed), *Fieldnotes: The Making of Anthropology.* Ithaca and London: Cornell University Press: 8; 24-5.

[13] Jackson, op. cit., note 12. Also see Jean Lave and Etienne Wenger (1991), *Situated Learning: Legitimate Peripheral Participation.* Cambridge: Cambridge University Press, and their discussion of learning as a social process, as part of which they highlight the importance in apprentice learning of "community lore" and stories, often depicting mistakes or times when things went wrong.

[14] James Spradley (1980), *Participant Observation.* New York: Holt, Rinehart and Wilson.

[15] Herbert Blumer (1969), *Symbolic Interactionism: Perspective and Method.* Englewood Cliffs, NJ: Prentice-Hall Inc: 40.

three kinds of ethnographic inquiry: comprehensive, topic-oriented or hypothesis-oriented,[16] and Spradley distinguishes between them, explaining that "comprehensive" ethnography 'seeks to document a total way of life,' "topic-oriented" ethnography 'narrows the focus to one or more aspects of life in the community,' while "hypothesis-oriented" ethnography is conducted when the ethnographer knows the community well enough to produce a set of hypotheses, on the basis of which s/he selects both a project to pursue and which data to collect for that project.[17]

In these terms, my investigation was topic-oriented; I did not seek to produce a comprehensive picture of St Z's, nor was I familiar with the community before I began my fieldwork, so I was unable to produce any hypotheses about it. If I had been able to gain access to the hospice at which I was volunteering when I first became interested in researching hospice care, this situation would have been different and I would perhaps have been able to develop hypotheses from which to start. However, since St Z's was new to me, I focused particularly on exploring the topic of the spiritual aspects of care in St Z's.

Ethnography follows a cyclical pattern. Once a project has been selected the ethnographer sets out to discover the implicit questions which the people in the social scene being studied take for granted, and which they are answering through their behaviour.[18] As the ethnographer discovers these questions, so s/he collects data on them and on the behaviour associated with them. Analysis of these data brings new questions to light, to which s/he then seeks to discover answers. Thus, the ethnographer moves from broad observations and broadly descriptive questions to more focused and selective observations and questions.[19] Writing becomes part of the analysis, since when the ethnographer attempts to write a description of the fieldwork site and the people, s/he may find gaps and uncertainties, which demand further investigation.

---

[16] Dell Hymes (1977), *Foundations in Sociolinguistics: An Ethnographic Approach.* Philadelphia: University of Pennsylvania Press.
[17] Spradley, op. cit., note 14: 31.
[18] Spradley, op. cit., note 14: 32.

Spradley argues that thinking of ethnography as a circular rather than a linear process in this way enables the ethnographer to keep a sense of perspective and not get lost in the data which s/he is collecting.[20]

Spradley's approach can seem to impose a too rigid structure on the ethnographic process, a structure which does not relate to actual fieldwork practice, and certainly in my experience things did not run in as smooth a way as his work might suggest. Ethnographers often identify this as part of the process of initiation into fieldwork, and frequently state that they would do or have done their subsequent ethnographies very differently from the first one.[21] Thus, Lave and Wenger's "apprentice learning," or the process of "learning-by-doing" which Jackson argues is the usual approach to graduate training in anthropology, was also true for me, and I too would approach doing another ethnography in a very different way. This does not, however, mean that I would discard Spradley's approach entirely, but that my understanding of it and of his aims, and of the aims and potential of ethnography, have changed through the process of doing fieldwork, as I will highlight later in this chapter.

PARTICIPANT OBSERVATION

Participant observation is central to ethnography, and means that the researcher joins the social scene in which s/he is interested, seeking to both participate in and observe what takes place. New members of any social scene learn the tacit rules of behaviour, and they have successfully learnt these rules when they no longer have to think about what they are doing.[22] Participant observers also seek to learn the rules of behaviour in a particular social setting, but participant observation differs from the usual social process

[19] Spradley, op. cit., note 14: 33-4.
[20] Spradley, op. cit., note 14: 35.
[21] See Jackson, op. cit., note 12.
[22] Spradley, op. cit., note 14: 53. Also see Michael Polanyi's discussion of "tacit knowledge" (1958), *Personal Knowledge: Towards a Post-Critical Philosophy*. London: Routledge and Kegan Paul. Again, this parallels Kuhn and the position of social constructivists which I outlined in the previous chapter.

in that participant observers maintain a self conscious, explicit awareness throughout their time in that social setting. Participant observers explicitly set out to learn the tacit rules which apply in the site where they are conducting their fieldwork, aiming to be simultaneously insiders and outsiders, being conscious of, and keeping records of, their immediate activities and those of others.[23]

Spradley argues that all people (whether consciously or not) use introspection to gain skill at following the particular sets of cultural rules which apply in a particular situation. Participant observers must be especially introspective, so as to use themselves 'as a research instrument,'[24] debriefing themselves after activities to find out what they did and what it felt like. It is important to note that using oneself as a "research instrument" may have emotional consequences for the participant observer, and I consider these in the section below when I discuss "leaving the field."

Spradley identifies various forms of participant observation, ranging along a continuum from "non-participation" (where the ethnographer only observes), through "passive" and "moderate" participation (where the ethnographer adopts an intermediate role somewhere between a participant – insider – and an observer – outsider), via "active participation" (where the ethnographer seeks to learn the same behaviour as other people in the scene being studied), to "complete participation" (studying a situation in which the ethnographer is already a participant).[25] He points out that it may be difficult for an ethnographer to produce ethnography from a position of complete participation, however, since s/he may be too familiar with the tacit cultural rules at work in that particular situation to be able to identify them fully.[26]

It is often said that ethnography seeks to make the strange familiar and the familiar strange.[27] Related to this, there are both advantages and disadvantages to

[23] Spradley, op. cit., note 14: 54-8.
[24] Spradley, op. cit., note 14: 57.
[25] Spradley, op. cit., note 14: 58-60.
[26] Spradley, op. cit., note 14: 62.
[27] See, for example, Harry F Wolcott (1999), *Ethnography: A Way of Seeing*. Walnut Creek, CA, London and New Delhi: Sage.

conducting ethnography in a new (strange) place or, on the other hand, in a place with which an ethnographer is already familiar. The fieldworker who has conducted ethnography in a place which is strange to her/him and to the potential audience seeks to make the beliefs and practices of the people she has studied seem familiar (not strange) to the audience, to whom initially those beliefs and practices might seem strange. Through this process the audience's own beliefs and practices (which are likely to be close to those of the ethnographer) are, explicitly or implicitly, highlighted, and appear less "natural" and inevitable. However, this latter step is not always explicitly taken. Thus, anthropology conducted as part of the colonial project non-reflexively explained the beliefs and practices of "natives" in relation to the unquestioned norms of the colonisers, thus leaving the familiar familiar and the strange strange (although "explained").[28]

Marilyn Strathern points out that doing ethnography "at home," which she calls "auto-anthropology," that is, conducting anthropology in the context which itself produced anthropology, is associated with its own particular problems.[29] Strathern argues that, since the "auto-anthropologist" shares concepts with the people s/he is studying, the specificity and context-dependent nature of those concepts is less evident, and the auto-anthropologist has to work harder to highlight the specificity and relativity of those concepts which s/he and the people s/he is studying hold. However, as I have indicated, reflexivity is not necessarily part of more culturally distant fieldwork, while Sharon Macdonald claims that reflexivity, precisely because it is not "routine," and so has to be worked at, is *more* likely to be present in anthropology conducted at home.[30] That is, while auto-anthropology is not necessarily reflexive, nor is any anthropology *per se*.

---

[28] In relation to this, see Peter Winch (1990), *The Idea of a Social Science, and its Relation to Philosophy.* 2nd edition. London: Routledge.

[29] Marilyn Strathern (1987), 'The limits of auto-anthropology,' pp. 16-37 in Jackson, A (ed.), *Anthropology at Home.* London: Tavistock: 28.

Further, even when conducting ethnography in one's own country one is not necessarily "at home." I feel that I neither conducted my fieldwork completely "at home" nor completely "away." To some extent I conducted it "at home" in that I conducted my study in the UK, so I shared many of the beliefs and attitudes of the people in St Z's. I also had prior experience of volunteering in a hospice. However, there was an extent to which I also felt that I was "away," in that St Z's was in some ways quite different to the hospice where I had previously been a volunteer. In addition, as a volunteer I had worked in a day hospice, and had had no significant experience on the wards of the hospice where I volunteered, so the wards on St Z's were a new experience for me. Further, St Z's was located in a small town in the West of Scotland, and, although I had lived in both Glasgow and Edinburgh, so had experience of the "central belt" of Scotland, I was not familiar with small Scottish towns. If I had conducted my fieldwork at the Edinburgh hospice where I had been volunteering, this would have felt much more like doing fieldwork "at home."

I will now move on to discuss gaining access to St Z's, and briefly outline key features of St Z's, before returning to consider in more detail how I conducted and recorded my fieldwork.

Why St Z's? Gaining access

Akhil Gupta and James Ferguson point out that an ethnographer seldom chooses a particular fieldwork site at random, but that this choice results from various ideological, structural and practical constraints which limit choices or create opportunities.[31] In addition, as Susan Strauss argues, constraints themselves are subject to external

[30] Sharon Macdonald (1997), 'The museum as mirror: ethnographic reflections,' pp. 161-76 in James, A, Hockey, J and A Dawson (eds.), *After Writing Culture: Epistemology and Praxis in Contemporary Anthropology.* London and New York, Routledge: 162.

[31] Akhil Gupta and James Ferguson (1997), 'Introduction,' pp. 1-26 in Gupta, A and J Ferguson (eds.), *Anthropological Locations: Boundaries and Grounds of a Field Science.* Berkeley: University of California Press: 11.

influences, such that events occur by chance as well as by design.[32] Thus, the ethnographer may not be in control of or have full choice over the situations in which s/he finds her/himself. S/he can, however, choose how to respond to them.[33]

As I mentioned in the previous chapter, I initially became interested in studying hospice care while I was a volunteer in the day hospice of a hospice in Edinburgh. I had been volunteering there for some time before I made the decision to develop a research proposal for a study of hospice care, and I felt that I had good connections with staff there, who seemed to feel, as I did, that I would be given access to do my fieldwork there. In the event I was denied access to that hospice (I explore this and related issues in the chapter which is reproduced as appendix VI[34]), and so, unexpectedly and at very short notice, I had to find another hospice where I could conduct my research.

I wrote to several hospices in central Scotland asking if I could come to visit them to discuss my project and the possibility of conducting my fieldwork on their sites.[35] Three hospices responded to my letter and invited me to visit them and discuss my research further, and one of these was St Z's, a hospice in a West of Scotland town fairly close to Glasgow.

On my first visit to St Z's, to meet the administrative manager, I felt welcomed and found the people there very forthcoming. In addition, I was interested in the structure and activities of the organisation. In particular, there were two different wards (an elderly care ward and a palliative care ward) in the hospice, and the social workers ran a weekly after school "drop-in" group for bereaved children, with an associated group for their parents or other family carers. Thus, when, a short while after this visit, the administrative manager contacted me to say that the management team were willing

---

[32] Susan Strauss (2000), 'Locating yoga: ethnography and transnational practice,' pp. 162-94 in Amit, V (ed.), *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge, 164.

[33] This is reminiscent of Karl Marx's comment that people make history, but not in situations of their own choosing.

[34] Bella Vivat (2002), 'Situated ethics and feminist ethnography in a West of Scotland hospice,' pp. 236-52 in Bondi et al, *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research.* Lanham, Maryland and Oxford: Rowman and Littlefield.

for me to conduct my fieldwork at St Z's, I accepted this offer, and I did not visit either of the other two hospices which had expressed an interest in my proposed fieldwork.

I then visited St Z's a second time, to agree the details of my fieldwork and meet the medical and nursing directors. I took with me copies of a document which contained a brief outline of my research and contact details for myself and my supervisors[36] and copies of the related consent form which I would ask interviewees to complete and sign.[37] The hospice managers subsequently showed other members of staff these documents, and told them that I was going to come to St Z's to conduct research, as part of which I would want to interview various people there. Thus, following a refusal of access to the hospice in which I had been volunteering, I very quickly and easily gained access to another site. In addition, as I have already noted, conducting my fieldwork at St Z's, a place which was completely new to me, rather than, as I had initially hoped, conducting my fieldwork in a place with which I was already familiar (that is, the Edinburgh hospice where I was already volunteering) had advantages associated with the novelty of the site to me.

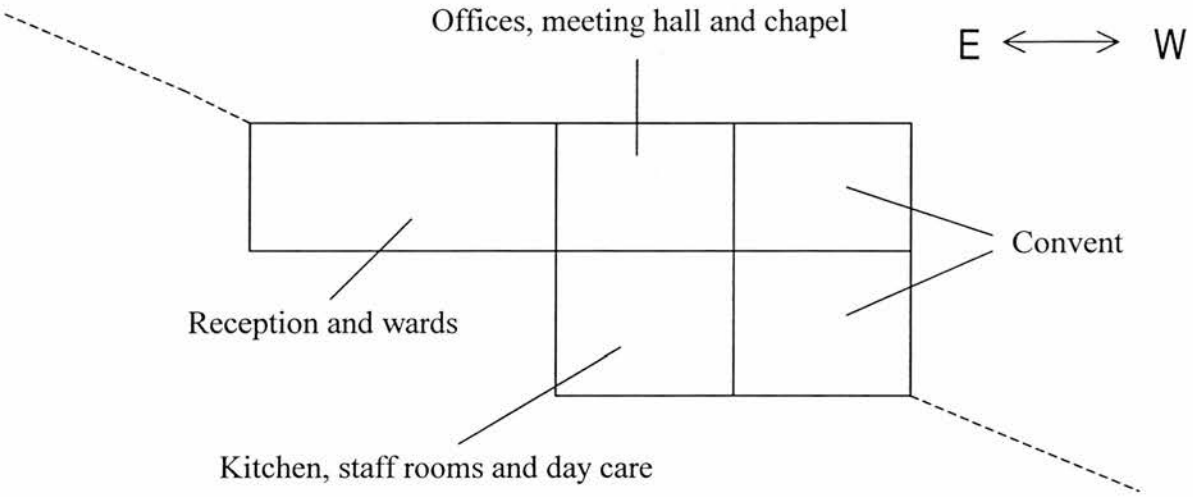
St Z's in brief

I conducted my fieldwork from February 1998 to April 1999, and this coincided with a period when a great deal of change was taking place in St Z's. When I began my fieldwork, part of the building in which the hospice was situated was a convent for the nuns of the Irish Catholic order which ran the hospice. A few nuns worked in St Z's, but most did not, instead being involved in community work in the town. The hospice had been built about ten years previously, and was built into the side of a hill. It was therefore partly on two floors (the western part of the building), and partly (to the east) on a single floor. The convent occupied part of both floors in the western part of the building. On the upper floor in the eastern part of the building were the reception area

[35] See appendix I for this letter.
[36] This was the information sheet which I later gave to each of my interviewees; see appendix II.
[37] See appendix III.

and the two wards: the elderly care ward (St E's), with 22 beds, and the palliative care ward (St P's), with 10 beds. Various offices, the meeting hall and the chapel were on the upper floor between the wards and the convent. Below these rooms, on the lower floor, were the kitchen and various staff rooms. The day care service, which provided support for people with a terminal diagnosis who were living at home, was located on the lower floor of the hospice, in four rooms which lay between the kitchen and those rooms of the convent which were on the lower floor (figure 3.1 below).

Figure 3.1: Layout of St Z's when I began my fieldwork (stylised and not to scale)



In December 1997, work began on building a new convent in the hospice grounds. This work was completed in August 1998, following which the nuns moved into the new building, and work began on converting the original building for use solely as a hospice. This entailed converting those parts of the building which had previously been used by the convent into a new day care facility on the lower floor, and administration and teaching facilities on the upper floor.

When this second phase of the building work began, day care moved from its long-established situation between the kitchen and convent on the lower floor of St Z's to the activity room of St E's, on the upper floor. Day care remained there until April

1999 when the conversion was finally completed. This was a significant over-run of the building work, since the original plan was that the new convent would be completed in six months and the extension in a further six months. This over-run and the consequent disruption of day care, whereby they moved from a large space with several rooms to a single room off a busy ward, resulted in pressure on and tension amongst staff, some of which I will discuss in later chapters.

Alongside this building and conversion work, St Z's was developing a 'Care-at-Home' service, which began in June 1998. A transition also began whereby St E's – the (22-bedded) elderly care ward – was ultimately to become the palliative care ward, and St P's – the (10-bedded) palliative care ward – was to become the elderly care ward. When I began my fieldwork, medical cover for St Z's was provided by a single full-time consultant, with local GPs visiting occasionally. Associated with the planned doubling of the provision of in-hospice palliative care, a new medical consultant began work at the end of August 1998. In addition, a "pastoral care coordinator" was appointed in April 1999, and this also resulted in some upset on the part of some members of staff (I discuss the layout, staffing and organisation of St Z's in more detail in later chapters).

The time I spent in St Z's, and where

From February 1998 until September 1998 I went to St Z's 3 or 4 times a week. I went every Tuesday and Friday, since there were fixed events on each of these days which I attended regularly. On Tuesdays, "case conferences" or "doctors' meetings" were held, from 12.30 until at least 1 o'clock, sometimes until 1.30 or 2. These meetings were attended by many of the nurses on both wards, the matron and deputy matron, the social workers, the day care coordinator, the physiotherapist, the medical consultant and the local GPs, and were a forum for discussing palliative care patients, focusing mainly on patients in St P's, but also including discussion of some palliative care patients in St E's and day care. I attended these Tuesday meetings on all but a few weeks during my

fieldwork, and most Fridays during my fieldwork I spent at day care (from 11 am to 3 pm) and at the children's drop-in (from 4.30 to 6 pm).

On Tuesdays and Fridays outwith these fixed times I spent time with people in different parts of St Z's: on the wards, in the tea bar, the reception area, and in various spaces between them. The additional 1 or 2 days during the week on which I went to St Z's I chose on the basis of factors such as whether particular people were on duty (I shadowed some nurses on their shifts, mainly on day shifts, though also on a few night shifts); whether I had arranged to interview people; whether particular people were in-patients; or whether events which were particularly interesting to me were taking place, such as "Mission Effectiveness."

From September 1998 onwards I went to St Z's less frequently, gradually reducing my time there to 2 days/week, then 1 day/week, then 1 day a fortnight, and so on, until I finally ended regular contact in April 1999, with my last fieldwork visit being on the day on which the opening ceremony for the new hospice extension was held. I did not entirely cease contact with St Z's after this, since I went there occasionally after this time, and from time to time I spoke with various people on the telephone. But my relationships with people in St Z's changed after April 1999 when I stopped regularly visiting St Z's.

When I was originally given access to do my fieldwork at St Z's no formal limits were identified to my fieldwork, but in effect I did not have open, unrestricted access at the beginning, since at the outset I was not able to go to all parts of the hospice. In particular, the managers did not immediately permit me to spend time on St P's. Instead, I was at first assigned to spend time on St E's. During this time managers were, in effect, assessing whether they felt it was appropriate for me to go to St P's, although this was never explicitly stated to me. This process was similar to that which managers used for most student nurses and for volunteers, thus suggesting that the managers originally categorised me along similar lines.

This situation also illustrates how, just as I was assessing/observing people in St Z's, so some of them were assessing/observing me, something which at times, and particularly in the early days of my fieldwork, took me by surprise. These observations of me by people in St Z's were in part linked to their various interests and motivations for granting me access to do my fieldwork there and/or for participating in my fieldwork, including interviews with me. These various positions only gradually became clear to me, similarly to Sharon Macdonald's comments on how she gradually realised that the various individuals and groups in the museum where she conducted her fieldwork had various interpretations, hopes and expectations of her study and its potential outcomes.[38]

Commuting and continuity

When I initially decided to do my fieldwork at St Z's, I was aware that its distance from Edinburgh was an issue which I needed to address. I could either move to, or closer to, the town where St Z's was, or commute from Edinburgh, either by public transport or by car (which would have necessitated me buying a car, since I did not have one). I felt that the upheaval of unsettling and resettling myself in or closer to the town where St Z's was would impact upon both my fieldwork and also my subsequent analysis and writing-up. In addition, I felt that I needed to stop volunteering at the Edinburgh hospice, since conducting fieldwork at St Z's meant that I would have less time for volunteering in Edinburgh, and also because if I continued volunteering there this could potentially confuse, and thus interfere with, my fieldwork at St Z's. However, I wanted to withdraw gradually, not abruptly, from my voluntary relationship with people at the Edinburgh hospice, and felt that I could manage to do this by remaining in Edinburgh and (so) gradually reducing my involvement.

[38] Thus, she says, some museum workers saw her as a potential ally; someone who was to be won over to "their side;" while others viewed her as a kind of management consultant, who, through her observations of how people made decisions would produce practical, policy-oriented suggestions for the museum (Macdonald, op. cit., note 29: 163; 166).

I decided, therefore, to commute by public transport, since I did not have a car, and it would have been costly to buy one. In addition, I felt that using public transport would allow me time to write my fieldnotes, and to reflect upon, plan, think, and process my fieldwork generally, which I would not be able to do if I was driving. This decision to continue living in Edinburgh and to use public transport to get to St Z's was unavoidably a compromise (as, indeed, would have been whichever choice I eventually made). However, commuting raised particular issues for my fieldwork. There were some advantages to commuting, since, as I had anticipated, it effectively provided me with an enforced place and time for reflection on my fieldwork.[39] However, commuting was also costly, not only in terms of both time and money, but also in terms of how tired I felt.

Before I began postgraduate study in Edinburgh I had been studying and working in London, where I was used to commuting over significant distances and travelling for over an hour to and from work. Because of this, I did not anticipate feeling as tired as I frequently did on getting home from fieldwork in St Z's, and I do not think that the tiredness I felt after my fieldwork was due to my commuting. I often felt tired on leaving St Z's, before I had even begun to travel home. I think my tiredness was less physical than mental, due to my intense attention when I was at St Z's, rather than to any heightened emotion. My experience of such extreme tiredness made commuting an increasing effort for me as time passed, and, with hindsight, was another factor which would have made driving myself to and from St Z's a bad option.

These various costs associated with being at St Z's meant that (as I noted above) I did not go there every day. However, I did go to St Z's regularly, and usually spent significant lengths of time there when I *was* there, since I felt that because it cost me to get there, I needed to make the most of my time there. I also felt that being there

[39] Elizabeth Young similarly comments that she felt that she was "in the field" when she drove to and from interviews since while doing so she was thinking about and/or listening to interview tapes (Young and Lee, op. cit., note 9: 103)

regularly, and for extended periods, at least at the beginning of my fieldwork, was important for establishing my credibility with workers as a serious person/researcher.

If I had moved from Edinburgh to do my fieldwork, it would have been different, since if I had lived in the town, or closer than Edinburgh, I would have been able to visit St Z's more frequently. In that case I would have visited for shorter periods, perhaps going there on most days, for at least a few hours, at various times during the day. On reflection I feel that this would have been preferable for that part of my fieldwork which I conducted on the wards, since I would have had more regular contact with workers and patients there, and thus more continuity, the importance of which became clear to me through doing my fieldwork. Continuity was significant in relationships with patients on the wards, since when they were admitted they usually stayed for several days, if not weeks at a time – the precise length of time a patient stayed depended on their particular needs and the reason/s for their admission to the ward. Thus different relationships formed between patients and people who were there every day or most days from those which formed between patients and people who were there less often (including not only myself but also part-time workers).

Day-to-day continuity was not an issue with regard to my relationships with people at day care, however. As noted, I went to day care every Friday, and this was similar to day care volunteers, who worked in day care on a fixed day (very occasionally two days) each week, and also similar to the pattern followed by those people with a terminal diagnosis who came to day care. These people were well enough to live at home; their illness was usually relatively stable; they received care and support from hospice and other health care professionals (oncologists, Marie Curie and/or Macmillan nurses, community nurses, social workers and so on) as necessary. In addition, they were assigned a regular day or days each week on which they could come to day care. Their contact with other people (staff, volunteers and other patients) at day care was therefore more intermittent than that for people on the wards. However, this intermittent

contact, occurring over extended periods – weeks, months, or even years for some patients – enabled people at day care to build close relationships with each other.

Thus, going regularly to day care every Friday gave me a sense of continuity and connection which was similar to that of the volunteers and people with a terminal diagnosis who attended day care. Despite this, it is also important to note that, even though continuity enabled me to build good relationships with some of the patients who came to day care, I did not have equally close relationships with everyone. That is, continuity alone did not guarantee the building of a good relationship.

Since I was not on St P's (the palliative care ward) on a day-to-day basis, I did not have a sense of continuity in my relationships with the patients there, and I built relationships with fewer patients there than in day care. However, through *not* having regular, daily contact with ward patients I gained insight into the importance of regular contact and continuity, as factors (although, as noted above, not the sole factors) in the building and maintaining of relationships between workers and patients, enabling the development of trust and "closeness."[40]

Different spaces – different places

In recent years, anthropologists have increasingly focused on the question of what is meant by "the field,"[41] and, as Susan Strauss points out, this is a relatively new interest in contrast to the ongoing interest in writing *about* "the field."[42] Anthropologists have spoken and written extensively about issues such as the importance of representation, and the linked issue of the relative power of different voices, and have commented at length on the general difficulty and challenge of the task of ethnography, but, until recently, they have said less about how the ethnographer constructs "the field" itself. Strauss argues that "the field" is not a bounded, isolable cultural whole, and probably

[40] See Jan Savage (1995), *Nursing Intimacy: An Ethnographic Approach to Nurse-Patient Interaction.* London: Scutari), and my discussion in later chapters of metaphors of movement and location.
[41] See for example the collection edited by Vered Amit (2000), *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

never was, but is instead something which an ethnographer constructs through the activities which occur between her choice of topic and her representation of it. That is, "the field" does not exist separately from the ethnographer, it is not somewhere which s/he visits, but is something which s/he constructs and produces (or perhaps co-constructs and co-produces with the people there).

In relation to this, although it would be possible for me to represent St Z's and/or the people there as a unitary entity, as, for example, "the hospice" or "hospice culture" or "the hospice community," I would not find it meaningful to do so. My fieldwork was not obviously multilocated, unlike Helena Wulff's research into ballet dancers[43] or Susan Strauss's study of a yoga community,[44] both of which studied people within and between several countries. However, there are parallels between their work and mine in that (as I discuss in more detail in the next chapter) it seemed to me that there were many differences between the various parts of St Z's, and, within each part of St Z's, there was some dissent and disagreement between people and their perceptions. That is, it seemed to me that there were multiple sites within the "single" site of St Z's, which differed significantly from one another, and multiple voices both within and between those sites.[45]

Since the different parts of St Z's were so distinct, and, as I have discussed, my involvement with these different parts of the hospice was not uniform, so too my fieldwork was not uniform, but took different forms depending on where I was and (therefore) what I was doing. Thus, I did not adopt a single one of the various possible types of participation observation for my fieldwork, but several different types, depending on where I was in St Z's and also how long I had been there (whether at St

---

[42] Strauss, op. cit., note 31: 164.

[43] Helena Wulff (2000), 'Access to a closed world: methods for a multilocale study on ballet as a career,' pp. 147-61 in Amit, V (ed.), *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

[44] Strauss, op. cit., note 31.

[45] See Arthur Kleinman (1995), *Writing at the Margin: Discourse Between Anthropology and Medicine.* London and California: University of California Press, for a consideration of multiple voices (amongst much else).

Z's in general or in the particular part of St Z's). My participation observation therefore ranged from non-participation in some parts of St Z's (particularly when I was at first in St P's), through moderate participation in most situations (including later on in St P's), to active participation in day care and the children's drop-in (where I was more of an active participant than an observer). Thus, my role in day care and at the children's drop-in was much more that of a volunteer, and my activities were similar to those of (other) volunteers in these settings.[46] On the wards, in particular when I was first on St P's, I took on a much more passive (non-participatory) and observational role. When I was in the tea bar, or other public areas of the hospice, I shifted between participant and observer, depending on whether people I knew were there or not, and whether or not I was directly interacting with them.

So my roles varied depending on where I was in St Z's, and, in relation to this, my balance between being participant and being observer also shifted. In addition, since ethnography is flexible and interactive, so that the ethnographer adapts her approach in response to the situation in which she finds herself, the focus and manner of my fieldwork did not only differ in different parts of St Z's, but also, within those different parts, changed while I was doing it. That is, my fieldwork changed as it proceeded, as the balance shifted between my participant and observer roles, and as I increasingly tested the knowledge I gained as observer through being a participant.

---

[46] My "active participation" in Spradley's terms (see above) is similar to the "active membership role" which Alison Langley Evans says she adopted for her ethnographic study of a palliative day care unit (Alison Langley-Evans and Sheila Payne (1997), 'Light-hearted death talk in a palliative day care unit,' *Journal of Advanced Nursing*, 26: 1091-7: 1093). Langley Evans and Payne draw this term from Adler and Adler's discussion of insider/outsider identity, and their identification of three categories of membership role for ethnographic researchers: "peripheral membership," where the researcher has partial insider identity; "active membership," where the researcher is more involved but is not fully committed to the goals and values of the members of the scene being studied; and "complete membership," where the researcher is already a member of the scene or becomes converted to full membership (Adler, PA and Adler P (1994), 'Observational techniques,' pp. 377-92 in Denzin, NK and YS Lincoln (eds.), *Handbook of Qualitative Research*. Sage, London). Langley-Evans participated actively in the various activities, trips and fundraising events organised by the day care unit, talking openly about herself and her research, which was thus entirely overt.

Many workers on St P's found my observational, non-participatory role difficult to understand initially, and a few continued to have this difficulty throughout my time there. I too found this observational role difficult in the early stages of my fieldwork when I felt that I did not really know or understand quite what ethnography meant in practice, and so had no real sense of what I was doing, and often felt that I was doing nothing at all. I found feeling that I was "doing nothing" difficult on a personal level, because I am generally uncomfortable with being a bystander and not directly involved in situations. But this personal feeling fed into and off a context where the general atmosphere was one where people were "busy" and always "doing something" (see next chapter), so one felt bad if one was "doing nothing." Thus, my discomfort with "doing nothing" indicated something about the culture of "busyness" in St Z's (and also indicated a contributory factor to my general feeling of comfort there, since the culture of St Z's had resonances with my own attitude).

Feeling rules

Young and Lee consider Arlie Russell Hochschild's concepts of "emotion work" and "feeling rules"[47] in relation to doing fieldwork, and claim that, although Hochschild's concepts may be highlighted by particularly sensitive topics such as Elizabeth Young's interviews with dying women (or, as here, studies of hospices), her concepts are relevant for fieldwork accounts in general.[48] Young and Lee argue that fieldworkers do emotion work when they attempt to manage what they feel (or admit to feeling) and various sets of feeling rules: what they feel they *ought* to feel, that is, what they feel people in their fieldwork site and/or social scientists feel or should feel. A fieldworker's emotional discomfort therefore highlights discrepancies between her/his personal and/or

[47] Arlie R Hochschild (1983), *The Managed Heart: Commercialization of Human Feeling.* Berkeley, Los Angeles, London: University of California Press.
[48] Young and Lee, op. cit., note 9: 110.

professional feeling rules and the feeling rules which exist for people in the fieldwork site (each of whom, of course, may have different sets of feeling rules).[49]

Young and Lee also suggest that inherent in fieldwork are tensions between fieldworkers' involvement, comfort and identification with people in the fieldsite, and that these tensions need to be explicitly addressed and managed, although they may never be resolved (since resolving one issue may exacerbate others).[50] Young and Lee point out that fieldwork accounts are often cast as journeys, with part of the process being emotional resolution, so that the emotions expressed in fieldwork accounts tend to be negatively cast, or as indicators of difficulties to be managed.[51] However, they argue that this part of the process is seldom examined in any detail, and claim that it is important to explore the reasons for any emotional difficulty which a fieldworker may experience, since a fieldworker's emotional difficulty is itself data; as Elizabeth Young states, "whatever I feel it is data."[52]

Young and Lee argue that, as part of Young's fieldwork, she attempted to manage conflicting sets of "feeling rules" – her own personal set and also feeling rules for nurses (people working in her fieldsite) and for sociologists – and was thus engaging in "emotion work," matching and comparing and managing her feelings with and in

---

[49] Deborah Lupton argues that implicit in Hochschild's analysis is the notion that a "true self" exists independently of social or cultural process, and that her analysis suggests that a person carries out "emotion work" to adjust the feelings of their "true self" to the "feeling rules" which exist for particular people (such as air hostesses or debt collectors) in a particular situation (Lupton (1998), *The Emotional Self*. London, Thousand Oaks, New Delhi: Sage: 26). Lupton argues that, contrary to Hochschild's analysis, social and cultural processes constitute notions of the self, and thus discourses on emotions, which include implicit or explicit "feeling rules," shape and reshape the "emotional self." That is, for Lupton there is no "true self" independent of social and cultural processes. However, saying this does not preclude the sense that people may have of having a "true self" (and feelings associated with that "true self") which is (are) present to a greater or lesser extent in different situations (such as with close friends or with acquaintances or work colleagues); the sense that different sets of feelings rules apply in different situations, so the "self" is performed differently – different amounts or kinds of feelings can be revealed or have to be managed as one's "true self" or "professional self."

[50] Young and Lee, op. cit., note 9: 111.

[51] Ibid. As I discuss in the next two chapters, people in St Z's also used a particular metaphor of movement when they spoke about dying, which they conceptualised as movement downwards.

[52] Young and Lee, op. cit., note 9: 108.

relation to her expectations of how fieldworkers "should" feel.[53] Young and Lee claim that Young's discomfort was an indicator of this process. However, a fieldworker's feelings of discomfort or difficulty are not the only data; so too are the fieldworker's feelings of comfort, identification and involvement. That is, both comfort and discomfort potentially convey information about the feeling rules which exist in a situation. So my discomfort with "doing nothing" in St Z's echoed that which workers felt.

My discomfort with "doing nothing" also meant that I was more comfortable with the active, participatory role which I was able to adopt in some parts of St Z's. As I have already noted, my role in day care, where volunteers played a key role, was effectively that of a volunteer. Volunteers were also fairly frequently/visibly involved with activities on St E's. That is, volunteers "did something" in day care and on the elderly care ward. However, volunteer involvement on St P's was rare, so it was difficult for me to find activities to do on St P's. This was particularly the case at times when the health of the patients on this ward was such that they did not want or were unable to speak with me, and I was unable to offer any physical care.[54] Because of my discomfort with "doing nothing," I tried hard to display that I *was* "doing something," particularly through publicly writing fieldnotes (I will return to this point in the following section).

I also increasingly aimed to minimise the time I spent "doing nothing" when I was on St P's, partly because of my discomfort with this feeling, but mainly because I found it so difficult to observe any aspects of care which seemed to me to be specifically spiritual. I therefore sought to move gradually from observer to participant on St P's, exploring and trying to imitate the qualities of interaction which I thought were present in those people I had identified and/or had identified to me as possibly practising

[53] Young and Lee, op. cit., note 9.

[54] As I began to shadow nurses and to participate more, I occasionally helped nurses lift patients and give them bed baths, but I was not allowed to do any of these things alone, because I was unqualified and uninsured.

spiritual care. Through my attempts to imitate the behaviour which I thought I observed from some workers (that is, by using myself as a "research instrument" and seeking to "learn through doing"), I developed my understanding of what I would call spirituality and spiritual care, which I discuss in later chapters.

I will now end my discussion of participant observation by detailing how I recorded my fieldnotes, following which I shall move on to discuss the interviews which I conducted in St Z's.

Fieldnotes

Spradley identifies four kinds of fieldnotes: the "condensed account;" the "expanded account;" a diary of personal issues; and analysis and interpretation.[55] The "condensed account" consists of key words and phrases, particularly verbatim language or "native terms," which the ethnographer records while in the fieldwork site. Later, the ethnographer develops this account into a detailed "expanded account," using the odd words and phrases from the condensed account as cues for jogging her/his memory. In the "expanded account" the ethnographer aims to record everything that happens on a particular occasion, including, and perhaps especially, repeated events and activities, for, as Spradley argues,[56] it is only through repeated observations and descriptions that the ethnographer perceives the complexity of seemingly simple situations.

The gap between condensed accounts and expanded accounts has consequences for how faithful the ethnographer's account is to what "actually happened." This gap also highlights the unavoidability of selectivity: although the ethnographer aims to record as much as possible, s/he is unable to note every event which occurs during her/his fieldwork, let alone all the details of every event as it happens. This meant that, as my fieldwork progressed, I found that some events might stimulate my memories of prior events, but that, since I had not noted those prior events when they occurred

[55] Spradley, op. cit., note 14: 67-9.
[56] Spradley, op. cit., note 14: 71.

(because at that time they had not seemed relevant or important to me), all I had were my memories of them. This simultaneously highlighted for me both the impossibility of noting everything, and also the importance of trying to note as much as possible of what happened in St Z's, however trivial it might seem, and also emphasised the importance of focusing particularly on repeated events and activities. It is worth noting, however, that less frequently repeated events and activities might be as important as those which happen repeatedly, but that if events are repeated infrequently their repetition may not be obvious. The central conclusion from this is that incompleteness and selectivity are inevitable, and can only be acknowledged and recognised.

Spradley suggests that, parallel with the expanded account, the ethnographer should keep a third kind of fieldnote, a diary of personal issues which arise during fieldwork: experiences, ideas, problems, confusions and so on. Entries are dated and used as a source of data when writing up later, so enabling the ethnographer to understand her involvement with and production of her research findings. These three types of fieldnote (condensed and expanded accounts and diary of personal issues) form what Spradley calls the "ethnographic record." His fourth type of fieldnote is analysis and interpretation, the link between the ethnographic record and the final written ethnography.[57]

Writing notes in the field

Throughout my time at St Z's I used a series of small, soft-covered notebooks for my notes. Since the notebooks were small and soft, I could keep the current one in my pocket, so it was always with me, both at St Z's and also while travelling to and from there. I used these notebooks for recording "condensed accounts," and also (since it would have been awkward, and confusing, to have more than one notebook in my pocket) to write down the third kind of fieldnote which Spradley identifies: the personal issues which arose for me while I was in the hospice.

[57] Spradley, op. cit., note 14: 72.

When I later wrote up my expanded accounts from the condensed accounts in these notebooks, I included my personal reflections or any thoughts I had had at the time of my fieldwork as I remembered them, or as they were stimulated through my reconstruction and consideration of events and interactions. In addition, while writing up my expanded accounts, I also wrote analytical or interpretive comments as they came to me, and, at other times, when I found myself thinking about my personal issues or interpretive questions independently from expanding my condensed accounts, I wrote separate reflective or analytic pieces.

Thus, I did not keep Spradley's four kinds of fieldnotes entirely separate. Nevertheless, I maintained a distinction between them, which, since I wrote up my notes on computer, I could mark easily by using bold or italicised text to highlight those parts of my notes which were my reflections and comments, analyses or interpretations.[58]

Owing to my different roles in different parts of St Z's, and my different approach to my fieldwork in each location, I did not write my condensed accounts in a uniform way. Thus, my different experiences in different parts of St Z's produced different kinds of records. Some of my condensed accounts are verbatim (or very close to verbatim) transcriptions. I have fairly detailed descriptions of some conversations and interactions during case conferences and in the tea bar, where I was able to take notes at the time that things were happening, or very shortly afterwards. During case conferences I took notes of the conversations as they went along, writing these notes on the sheets listing hospice patients which Dr 5's secretary[59] distributed at the beginning of each case conference. These notes were therefore often verbatim, although at times, particularly if a lot was being said which was of interest to me, or if people were talking quickly or

[58] The ease and low cost of access to computer technology is an advantage of working at the end of the 20th century, as opposed to when Spradley was writing in 1980.

[59] I explain my use of codes and pseudonyms for people in St Z's later in this chapter, but here I will note that, although I identified the medical director as "Dr 5," I do not have a code for his secretary because I did not talk with her in any depth.

more than one at a time, I would summarise or paraphrase what was said.[60] When I got home from St Z's, I prioritised expanding my notes from the case conferences because I noted down a significant amount of material during these meetings, using many abbreviations. I knew, therefore, that these notes would become increasingly difficult to decode as time passed.

Another situation where it was possible for me to take notes directly was when I was in the tea bar, where I often sat at one of the smaller tables with a cup of tea and wrote notes on my fieldwork, which at times included observations from the tea bar itself. Thus, as with case conferences, there were times when I was able to transcribe conversations in the tea bar virtually word for word.[61] At other times, people might come in whom I knew, or, if the tea bar was not particularly busy, I might talk with the woman who was that day's tea bar volunteer. In these latter situations I closed my notebook while I was talking, although I might subsequently make notes on what had been said and/or what had happened there.

In other situations – such as in the children's drop-in, when I was shadowing nurses, and/or when a great deal of activity was taking place on the wards, or on some occasions in day care – I did not take notes while events were happening, mainly because it was difficult to write fieldnotes while other activities were going on. I therefore had to produce my condensed accounts relating to these situations some time later (sometimes minutes later, sometimes an hour or two), and usually when I was in other places: the tea

[60] Initially people at case conferences commented on my note taking, but these comments gradually decreased, partly because Dr 5's secretary was also taking notes, and also because people began to know who I was and became used to me sitting and writing notes – so, for example, Dr 5 came into St P's at one point when I was there writing notes and called me a "fly on the wall" – see my earlier comment on how people in St Z's were also observing me.

[61] This latter situation obviously raises questions concerning access and the ethics of research. Although the managers of St Z's gave me open, unrestricted access to the hospice, it was impossible for me to introduce myself to every single person who came and went, so not everyone there knew (or could know) what I was doing. Thus there was an extent to which my fieldwork was effectively covert, even apart from the wider questions of who grants access and who is not consulted when access is given, and of the extent to which people understand the meaning or possible consequences of research. This is a point at which my personal ethics and how I decided which material to use and which not to came into play, an issue which I discuss elsewhere (Vivat, op. cit., note 34, and appendix VI).

bar, the nursing station, or on the train going home. In these latter cases I was more reliant on my memory to reconstruct events and conversations, and so I could not remember all the detail of these situations, particularly the precise phrasing of people's remarks in conversation.

At times when I was first on St P's, the palliative care ward, I sat in the toilet to write and think about my notes, since this was a place which offered peace and privacy. However, after I had been going to St P's for a while, I moved from wanting privacy in which to write my fieldnotes to wanting to make my writing of fieldnotes as visible as possible. This was partly because, as I noted in the previous section, I felt uncomfortable when I felt that I was, or could be taken by workers to be, "doing nothing." As I also noted, my discomfort was not only because I personally felt that I was "doing nothing," but related to the general culture of "busyness" on the wards in St Z's, so this sense that I was "doing nothing" was not only mine, but also that of some workers.

Workers either expressed this perception to me directly ("what are you doing again?"), or conveyed it more indirectly. For example, on one Friday afternoon I was sitting by the nursing station in St P's, talking to a couple of nurses. I planned to remain on St P's until the night shift began, and was not intending to go to the children's drop-in that evening. AN 30, who was on the volunteer rota for the children's drop-in that evening, asked me to go in her place because she had commitments after work. That is, AN 30 thought that I was "doing nothing" on St P's, and so was free to go to the drop-in. Because of these kinds of reactions, I often particularly sought to display that I was writing fieldnotes at times when there was little happening in which I could participate, in which case I might appear to be "doing nothing" (and therefore to be free to do other things). Another reason for my decision to visibly write notes was my feeling that, because workers did not really understand what I was doing, or did not think that I was

doing anything, they might say things in front of me which they would not say if they fully understood what my research meant.[62]

Sharon Macdonald discusses the public writing of fieldnotes, and says that, as she became increasingly aware of the differences between staff in the museum where she was conducting her fieldwork, so she became increasingly self-conscious over what and when to write.[63] She says that writing fieldnotes was "an act which was imbued with the meaning that something meaningful was going on," and, precisely because of this, there were some situations in which she did not write fieldnotes, because she felt that her writing would have been conspicuous.[64] That is, it seemed to Macdonald that her act of writing was significant to the people she studied, and, because of this, there were some situations in which she did not take notes.

For me, for most of my fieldwork, the situation was quite the opposite. Although initially I concealed my fieldnote writing, in part because I thought visible writing might inhibit people's thoughts and actions, at a fairly early stage I began to feel that, although the people at St Z's perhaps recognised my writing fieldnotes as "doing something," they did not perceive it as meaningful or significant to anyone other than me. As a result of this, I became anxious that they should recognise the significance of my note taking, including its potential consequences for them, and this was why I tried to make it more, not less, conspicuous. That is, I sought to visibly write fieldnotes not only so that workers would see me as "doing something," but also in order to signal to workers that I *was* "doing something" which might perhaps have repercussions for them.

---

[62] My concern about this links to my comment in the previous footnote concerning the ethics of research (again see appendix VI).

[63] Macdonald, op. cit., note 29: 164.

[64] Macdonald (op. cit., note 29) points out that her self-censorship meant that "total inscription" did not happen, although, as she also highlights, and as I indicated above, total inscription is in any case impossible.

Writing my expanded accounts

As I noted earlier, I often found that I was exhausted when I got home from St Z's. I was often too tired to expand my fieldnotes to a more detailed text (Spradley's "expanded account") immediately after returning home, but did so the next day or over the course of the next few days. However, since over the following days I was also returning to St Z's and writing more fieldnotes, I did not always have time to expand all my fieldnotes from each visit. Instead, I prioritised those particular episodes which, as time passed, and as I reflected on my fieldwork, seemed especially significant to me. So some of my fieldnotes were never expanded but still remain in note form ("condensed accounts").

When I was writing expanded accounts from my condensed accounts, I found that I was able to recall some things clearly from minimal notes; while other notes seemed to me more cryptic and I found the details difficult to remember or retrieve from these. I find it difficult to identify which characteristics enabled me to recall some things more easily than others, other than noting that (unsurprisingly) it was relatively easy for me to recall striking (unusual) events, at least in broad terms, if not necessarily in detail, whereas more mundane and repetitive events were less memorable individually. However, these latter, repeated events were more memorable over time, since, as I have noted, they had a cumulative effect, being reinforced by their repetition.

My written (documented) fieldnotes therefore vary in terms both of when I made my condensed accounts and of when I expanded them, which means that they also vary in their detail. In addition, of course, the delays between when I wrote my condensed accounts and my later expansions of them have consequences for the accuracy of my ethnographic account (as does my subsequent recalling of events which I did not note down at the time).

But, arguably, fieldnotes are not only written texts, despite what, for some ethnographers, can seem an obsession with, even a fetishisation of written fieldnotes and interview transcripts, associated with the perception that written texts have greater

authority than memory. In her survey of anthropologists' attitudes to their fieldnotes, Jean Jackson notes that many anthropologists say that they did not fully expand all of their fieldnotes.[65] Jackson also illustrates the many different ways in which people produce and think of their fieldnotes, and argues that fieldnotes are not only written texts, but are also embodied in the person and memories of the ethnographer.[66] That is, "I am a fieldnote" in that my memories of my experiences in St Z's, which are now part of me, can also be thought of as fieldnotes, which supplement and/or duplicate my written records.

In addition, "I am a fieldnote" in the sense that I acquired knowledge during my time in St Z's which I am not necessarily able to write down. This knowledge is part of me, part of the process through which I have gone over the last few years, and so it has changed me, but it is not necessarily "write-able," although it can be discussed indirectly, in terms of how I have changed.[67] This kind of experiential knowledge is important both for anthropologists and also for the feminist/postcolonial theorists of knowledge whom I discussed in the previous chapter. In relation to anthropology, Strauss argues that it is important to engage in practically based research and discuss its impact explicitly,[68] and she points out that much work on yoga focuses on textual tradition and ignores practice, yet practice is central for yoga.[69] Conversely, interview material is in textual form

---

[65] Jackson, op. cit., note 12. Also see Roger Sanjek (1990), 'Fieldnotes and others,' in Sanjek, R (ed), *Fieldnotes: The Making of Anthropology.* Ithaca and London: Cornell University Press.

[66] Jackson, op. cit., note 12.

[67] As I will discuss later in this thesis, it is possible that it is only possible to point to spiritual understanding, not to convey it directly. That is, "the Tao that can be talked about is not the Tao" (Lao Tzu (translated and introduced by DC Lau) (1963), *Tao Te Ching.* Harmondsworth: Penguin: 15-16).

[68] Strauss, op. cit., note 31: 187-8. Strauss says that practising yoga herself gave her an insight into how her discussants thought about it, and points out that one issue to do with the study of yoga is the scholarly credibility of a research topic which depends on experiential data, which demands that she walk a tightrope between 'popular' descriptions of practical experience and 'academic' analyses of texts and reported speech. For discussions of how to use experiential knowledge in anthropology see Kirsten Hastrup and Peter Hervik (eds.) (1994), *Social Experience and Anthropological Knowledge.* European Association of Social Anthropologists, London: Routledge and Michael Jackson (ed.) (1989), *Paths Toward a Clearing: Radical Empiricism and Ethnographic Inquiry.* Bloomington: Indiana University Press.

[69] Strauss cites Mircea Eliade's comments that while what he had learned through the practice of yoga had a profound impact on his understanding, the details of this were not relevant to his textual analyses, and so he did not discuss these details (Mircea Eliade (1981, translated by Mac L Ricketts), *Autobiography,*

(transcripts) and can be analysed as such (although such material is not transparent, as I discuss in the later section on discourse analysis). I will now move to discuss issues relating to the taped interviews which I conducted with workers in St Z's.

Interviews

As I noted earlier, ethnography changes in interaction with events in the fieldwork site, and a key point where this occurred for my work was in relation to the taped interviews which I conducted, which were solely with workers. This was not my intention when I began my fieldwork, but was something which evolved as my fieldwork progressed, for a variety of reasons. Initially, I found that it was difficult to schedule interviews with both workers and patients. I gradually became aware of how quickly and unexpectedly patients' health could change, and this meant that if a patient was unwell or personal issues arose for another patient, a worker I had planned to interview might be unexpectedly involved with a patient, or called away to see them during or before beginning the interview with me. Alternatively, if the ward had been very busy on a particular day, a worker who had previously agreed to talk with me at the end of her shift might in the event feel too tired to do so. Additional factors which unexpectedly caused planned interviews with workers to be cancelled were that workers might, for various reasons, exchange shifts with someone else at short notice, or workers might unexpectedly encounter problems with their child care arrangements, so I could not interview them as we had planned. All these factors meant that I became used to having to schedule and reschedule interviews, and to the long time it might take before I could conduct a particular interview. So, for example, I began trying to arrange a time to interview SN 17 in June, and finally managed to interview her in November.[70]

Volume 1: 1907-1937 Journey East, Journey West. San Francisco: Harper and Row: 190, cited in Strauss, op. cit., note 31: 188).

[70] This difficulty meant that I was unfortunately never able to schedule a taped interview with SN 25 (a night sister on St P's who I will discuss later), although I did have several un-taped conversations with her.

It was thus difficult to schedule interviews with workers, but difficulties also arose when I wanted to interview patients, which at the beginning of my fieldwork I planned to do. I felt that it was important to have established a relationship with a patient before I asked them if I could interview them about issues relating to the spiritual aspects of care, since this was a potentially sensitive area to talk about. I felt that I managed to establish good relationships with some patients in day care and, at the beginning of my fieldwork, there were a few occasions on which particular patients initiated conversations relating to questions of meaning (such as asking "why me?") with me. I asked a few of these patients if they would be willing to talk with me in more detail, and for this future conversation to be taped, and they agreed. However, before the interviews could take place these few people variously died, or were admitted "upstairs," or into hospital, and/or began to "go down."[71] So, for example, a patient who had felt well enough to agree to be interviewed was in the event not well enough, and/or was too distressed, to be interviewed on the day arranged, while another patient who had agreed to be interviewed on their next visit to day care was too unwell to come as planned.

Thus, changes in patients' health – which, as I noted earlier, could occur without warning, even in the case of people whose health was apparently stable – meant that it was not always possible to interview a particular patient as arranged, or I did not feel that it was appropriate. Thus, although it was easier to arrange to interview patients than workers, the early arrangements which I made were not fulfilled. The difficulty of carrying through these future arrangements increased my awareness of the necessity of "seizing the moment," that is, that it was important to take the opportunity to talk about things with patients if it arose, since it might never arise again. This also, of course, gave me additional insight into workers' interactions with patients, where, similarly, it was important to seize such opportunities when they arose.

[71] People in St Z's frequently used this metaphor to talk about people who were becoming less well, but this paraphrase fails to convey the sense of someone moving away which was central to the metaphor of "going down." In later chapters I will return to discuss the significance of patients' location and movement

So, the arrangements to interview patients which I made early in my fieldwork did not result in interviews. Later, as my fieldwork progressed, I came to the decision that I would not conduct taped interviews with patients, because, as I discuss in more detail in chapter five, it seemed to me that many workers avoided publicly engaging with patients' spiritual or existential concerns or questions. It was difficult to say whether this public avoidance was continued in private, but, because I felt that workers' engagement with patients' spiritual concerns was rare, I also felt that I had to act on the basis of this perception, whether it was "correct" or not. I increasingly felt that I could not be sure whether, following an interview in which I asked patients about their spiritual concerns, and which could therefore potentially raise difficult and/or painful issues for patients, there would be anyone around who would be able to help them with those issues. Nor could I guarantee that I would be there to follow the conversation up on the following day, and this was important because, as noted, things could change rapidly for patients.

I also felt that the distinction between researching and providing spiritual aspects of care was a fine one. I felt that asking people about their spiritual concerns was very close to providing spiritual care, particularly in the kinds of lengthy, detailed, probing discussions which would occur in taped interviews as opposed to the relatively short conversations which occurred in other situations. I did not feel it was appropriate for me to engage patients in detailed discussion about their spiritual concerns if I did not feel that there was anybody around to refer patients to, and I did not feel qualified to conduct spiritual support.[72]

Thus, I did not feel that it was appropriate for me to conduct taped interviews with patients, since not only would they not necessarily benefit from these interviews,

within St Z's, both literally and metaphorically, and to consider how people in St Z's used physical metaphors of location and movement when they spoke about both spirituality and dying.

[72] As I discuss in the next chapter, this resonated with workers' sense that "I'm not qualified" or "it's not my job" in relation to certain actions.

but such conversations might even have a negative effect.[73] So, after my unsuccessful early arrangements to interview day care patients, I did not rearrange the interviews. It is of course possible that, because patients' health changed so quickly and unexpectedly, I would have been unable to conduct many interviews anyway, but it is impossible to say whether this would have been the case.

Thus, I did not conduct any tape-recorded interviews with patients. However I did have in-depth, non-recorded conversations with some patients at moments when that was possible, and if patients initiated such conversation by, for example, asking the "why me?" question. These relatively brief but frequent dialogues, initiated by patients, seemed to me more appropriate than lengthy interviews. The longer I was in St Z's, the more understanding I had of how to respond when patients initiated intimate conversations, but this also increased my feeling (reinforced through the interviews I was conducting with workers) that such conversations might leave patients with needs which I could not be sure would be met. I felt that, beyond refraining from asking probing questions about their experiences in St Z's, and following the patient's lead, I could only rely on my intuition, my feelings, and my relationship with each individual patient to trust that the patient would only raise issues with which s/he was comfortable.

So, in the end I conducted a total of 24 tape-recorded interviews with individual workers in St Z's. At first, I set out to obtain an overview of the various perspectives on spiritual aspects of care held by various workers. I therefore sought to speak to a range of workers, and I selected interviewees accordingly. However, as it increasingly became clear to me that few people identified any specific spiritual aspects of care, I became more selective in how I chose my interviewees, seeking to speak only with those people who had, or who I thought were more likely to have, views on spiritual aspects of care.[74]

My interviews were largely unstructured. Although I had themes which I sought to address, and my general approach to each interview was broadly the same (although

[73] I consider the ethical question of raising issues and leaving vulnerable people with them in Vivat, op. cit., note 34 (appendix VI). Also see Young and Lee's discussion of this (op. cit., note 9).
[74] I discuss this point in more detail in chapter five.

refined and developed with my experience and reflections over the course of my time in St Z's), I generally followed my interviewees rather than a predetermined script, which made each interview very different. The interviews varied in length from 40-45 minutes (about one side of a 90-minute tape) to 90 minutes (both sides) or occasionally even longer (extending onto a second 90-minute tape).

Before each interview I gave the person I was interviewing a copy of the sheet with information about my research (appendix II), and two copies of the consent form (appendix III). They and I signed both copies of the consent form, then the interviewee kept one copy, and I kept the other. I asked them if they had any questions or problems, and reassured those who were nervous about being tape-recorded that the tapes were entirely confidential and that they would only be heard by me. I began each interview in a similar way: asking my interviewee to tell me how they came to work in St Z's and what they did there. I pursued any points they mentioned which I found of interest, focusing particularly on anything they said which I thought might provide an opening to talk about spirituality or spiritual aspects of care, such as their attitudes towards patients and/or other workers or any comments they made which I thought indicated something about their understandings of care.

In the later interviews, as I was becoming increasingly aware of how difficult people found questions around spirituality, I began opening the interviews by saying that I might ask questions which my interviewee might find difficult to answer, but that they should not think that of that as a problem, since many people to whom I had spoken had found it difficult to talk about spirituality.[75] People found it difficult to talk about these issues even when it seemed to me that they were trying to do what they felt would please me or help me, by trying to give me what they thought would be "good" or the "right" answers; what they thought I wanted to find and/or what they thought I would find useful or helpful. Despite their attempts to do this, many of my interviewees said that they did not know, and/or could not say, what spiritual care was, and apologised for this. Again, I

[75] I discuss this in more detail in chapter 5 on spiritual aspects of care

repeatedly reassured them that I did not think of this as a problem, nor a failing on their part. I discuss my findings from these interviews in chapter five.

Leaving "the field"

Nancy Howell states that fieldworkers commonly report feeling depressed and/or lonely when in the field,[76] and she argues that these feelings are particularly associated with the psychic difficulties of being in a different culture.[77] I experienced neither depression nor loneliness while doing my fieldwork at St Z's. As I have noted, to some extent I was doing my fieldwork "at home," so, although some activities and attitudes within St Z's were unusual for or new to me, I did not experience the culture as profoundly different. I was also sympathetic with a lot of the values expressed by people in St Z's.

I have also noted that there were times early in my fieldwork when I felt that I was "doing nothing" and doubted whether what I was doing was fieldwork, and/or whether I was "doing fieldwork" correctly. Conversely, on occasion throughout the course of conducting my fieldwork I experienced intense boredom and feelings of "nothing happening." However, as I became more comfortable, and began to see patterns in the activities I was observing, and fully to understand what I was doing, what I was doing began to make more sense to me, and I started to feel that it had some value.[78] In addition, I felt personally satisfied and rewarded by my interactions with both workers and patients in St Z's, feeling, in particular, privileged by the intimacy of my interactions with many patients.[79] I also felt that I was supported both by people (workers and patients) in St Z's, and also by the occasional meetings which I had with my supervisors during my fieldwork.[80]

---

[76] Howell, op. cit., note 11: 152-3.
[77] Howell, op. cit., note 11: 155-6.
[78] Thus my feelings while doing fieldwork were largely positive, and I did not experience the psychic difficulties which Howell discusses.
[79] I discuss this further in my empirical chapters.
[80] Such regular supervisory meetings are unusual for ethnographic research (or occur only at long intervals), since the ethnographer is usually "in the field," that is, away from home.

What I did experience very strongly was what Howell calls "repatriation stress." She acknowledges that this is a rather clumsy term, but says that it is a term which most anthropologists seem to understand and which they report as being a common hazard. She describes repatriation stress as a sense of alienation and dislocation from one's own society after returning, the feeling that life does not make sense there, and the missing of people, sights, sounds and smells from the studied culture, which in some way has replaced the home culture in the ethnographer's affections. She says that some anthropologists sink into a deep depression after returning from the field, feeling that they have ruined their life and membership in their own society, but in most cases this sense is transitory, and usually passes after some months.[81]

This description of 'repatriation stress' resonates powerfully with me. I found leaving St Z's and returning full-time to academia very difficult. I felt very lonely, suddenly feeling very much on my own in contrast to having been, albeit intermittently, part of a community. I also felt protective towards the people I had studied, and extremely aware that the people around me in academia lacked knowledge about hospices in general and about this organisation in particular; I was aware of the (inevitable) limits of my reports on my fieldwork (which could only ever be partial and incomplete), and of the risk that other people might make interpretations and judgments about people in St Z's on the basis of those limited reports.

Helena Wulff points out that there is a significant anthropological focus on issues around gaining access to "the field," which is evident both in the methodological literature and in stories which anthropologists tell one another about their fieldwork.[82] Wulff says that in such stories, anthropologists stress the initial hardships they encountered, including such issues as having to deal with marginality, and the cultural *faux pas* which they may have made in the early stages of their fieldwork, while portraying the exit from the field as largely unproblematic. However, as Strauss points

[81] Howell, op. cit., note 11: 160.
[82] Wulff, op. cit., note 43: 155-6.

out, each research project has a point of ending or abandonment, and the ethnographer has to decide when or how much is enough.[83] Wulff also claims that fieldwork stories of the type she discusses construct fieldwork as something which is conducted during a liminal, finite period of time, and (thus) as something which the fieldworker leaves behind on returning to her "real life," but that it is difficult for an ethnographer who has conducted fieldwork "at home" to break off all contact with the field once fieldwork as such is complete.[84] In addition, technologies such as the telephone and e-mail make it harder for the ethnographer (if s/he should wish to do so) to cut off all communication with the people s/he has been studying, even if they are people "away from home."

Endings and associated issues around loss are particularly important in relationships with people in hospices, where they are significant not only for patients, but also for workers and for volunteers (who are often themselves bereaved people).[85] Such issues were therefore present in relation to ending my fieldwork at St Z's, where they were particularly relevant for the bereaved children at the drop-in, but were also significant for other people there, including myself. I had been aware of the importance of "managing" the ending of my volunteering at the Edinburgh hospice which I mentioned earlier, where I was far less involved than I was with St Z's. I felt that it was therefore essential for me to "manage" leaving St Z's, and I gave some thought to how I would end my fieldwork, finally deciding that I would gradually reduce the frequency of my visits to St Z's, rather than abruptly stop visiting.

As I noted earlier, I conducted the main part of my fieldwork between February and September 1998, going to St Z's three or four times per week during this time. From September 1998 until April 1999 I gradually decreased the frequency of my visits to St Z's. By the end of October 1998 I was going to St Z's once or twice a week; this reduced to two or three times a fortnight during November and December 1998, once a

[83] Strauss, op. cit., note 31: 164.
[84] Wulff, op. cit., note 43: 155-6.
[85] On loss see, for example, Peter Marris (1986, revised edition), *Loss and Change*. London: Routledge and Kegan Paul.

fortnight in January and February 1999, and after that I went a few times more until I finally stopped going altogether in April 1999. On each visit I tried to spend some time in day care and the children's drop-in (I therefore often went to St Z's on Fridays). When I was there I usually tried to also visit St P's, particularly if a palliative care patient I knew previously and/or from day care had been admitted or readmitted, but I would not spend time with patients who I did not already know. This latter point again highlights the relevance of continuity: if I was not going to return to St Z's for a week it would be difficult to establish links with patients on St P's with whom I had no pre-existing connection. This again raises the ethical question of "who benefits?" since, while I might have gained something from this, these patients probably would not.

As my frequency of visiting St Z's decreased, so my relationship with the hospice became more as it had been at the beginning, and yet at the same time it was different. I felt more of a stranger, as if I was beginning my fieldwork again: new patients arrived (this of course was usual for St Z's), but also, associated with the opening of the new extension, the expansion of day care, and the changing round of the wards, some of the usual activities changed, and new workers and new volunteers arrived. I forgot (had to re-learn) things like people's names and who did what. Yet, at the same time, it was all very familiar.

For me, this highlighted a central paradox of ethnography whereby the ethnographer, although s/he is in some ways trying to become an "insider" and get close to insiders, is irreducibly an "outsider." This is not only because the ethnographer is always in part an observer, but also because, as is known from the beginning, her "insider" status is only temporary; if the ethnographer is not to join the community s/he has been studying s/he ultimately has to leave the fieldwork site, and so end or at least alter her/his relationships with the "real" insiders. If the ethnographer has performed well as a "research instrument," however, s/he will have built meaningful relationships with people in the community being studied, including encouraging them to trust and

confide in her/him. This emotional involvement means that ending or changing those relationships is difficult emotionally.

Even though I managed leaving St Z's gradually, I found finally leaving difficult, and to some extent painful, since I was personally involved with and attached to people there, and leaving meant breaking these attachments. There are, of course, parallels here with the inevitable breaking of attachments which people in hospices form with people who are dying. However, when one enters into a relationship with a person who has a terminal diagnosis, the knowledge is always present that that relationship will definitely end in the relatively near future, although exactly when is uncertain (and – as I discuss in the next chapter – it can still be shocking when a "terminally ill" person dies unexpectedly, even for people who have significant experience of working with dying people). Of course, the experience is different again when both people in the relationship have a terminal diagnosis (when both are patients), which means that the end of the relationship can involve the death of either (again, I discuss this more in the next chapter). Conversely, when relationships are built between people neither of whom has a terminal diagnosis, these relationships are perceived as potentially ongoing (indefinite). So, there was an element of choice involved in my ending/changing these relationships by leaving St Z's, which is not present when a relationship is ended entirely by external force of circumstance, such as death (although, of course, people who are dying (and/or their friends and relatives) may choose to withdraw from relationships).

I think it is perhaps hard, if not impossible, to be involved as a participant in an organisation of this kind and not develop attachments to the people there. Regardless of whether attachment is to be recommended as a research approach, it would be difficult to maintain detachment, which implicitly includes the self-conscious monitoring of oneself, over a long period as a participant.[86] The difficulty with maintaining a self-conscious awareness of one's actions is what underpins the argument that sustained immersion in

[86] The detached colonial anthropologists and ethnographers from the Chicago school were observers, who did not participate, or did so only to a limited extent.

the field will result in "good data;" it is claimed that, even if, initially, the people being studied attempt to put on a false front for the benefit of the ethnographer, they cannot maintain this for any significant length of time, but will eventually return to their usual habits. However, this difficulty with maintaining a false front over a lengthy period of time applies equally to ethnographers, who cannot maintain an image of "the ethnographer" over long periods, but become their "normal," "true" selves.[87]

I feel that my feelings of attachment to people in St Z's were exacerbated because it seemed to me that I had more in common with many of the workers there than with many people I had met in academia. I also felt that the work which people were doing in St Z's was something which I could be doing. Of course, my experience was not equivalent to a worker's, but closer to a volunteer's: I was *not* an employee of St Z's, I did not have the accountability of an employee, and I was never fully part of St Z's in the same way as an employee, since it was my choice to be there, and my choice, ultimately, to leave, and this was reflected in my relationships with people there. Nevertheless, I did feel that hospice work was a road which I might well have taken in the past, if I had been aware of it as a medical student, and could still take now. The people working in the hospice also recognised this, and they "talent-spotted" me, asking questions and making (unsolicited) comments such as: "What are you going to do when you finish your research?" "You should work with people," "I'm sure there's something you could do in hospice," "Have you heard about these spiritual care departments the NHS is developing?"[88]

However, my feeling that St Z's was a route which I could have taken could, of course, apply to any fieldwork situation and perhaps particularly to fieldwork conducted "at home," and Helena Wulff suggests that this kind of experience is common in

---

[87] A classic example of this is Elenore Smith Bowen (1954/1964), *Return to Laughter*. New York and London: Doubleday.

[88] This "talent-spotting" was something which I was aware happened in relation to student nurses, and so what workers saw in me was perhaps an indicator concerning the perceived advantageous characteristics of workers. It also illustrates how workers were taking care of me, looking after me, by giving me suggestions for my future. I return to these issues in the next chapter.

fieldwork. She says that although fieldworkers inform the people they study that they will eventually leave, many report on phases of what is termed "going native,"[89] being asked to stay permanently in the fieldsite, and contemplating this as a possibility.[90] Wulff quotes from Evans-Pritchard: "an anthropologist has failed unless, when he [*sic*] says goodbye to the natives [*sic*], there is on both sides the sorrow of parting."[91] That is, if the ethnographer does fieldwork "well", both s/he and the people s/he has been studying feel that s/he belongs in the fieldsite; there is attachment on both sides.

Wulff argues that fieldwork is often not as compartmentalised a practice as some ethnographers represent it as being. The fieldworker has to walk a tightrope between her feelings for her discussants or informants and using her relationships with them for the purposes of her research. In some situations, people who have been key informants may survive as friends after fieldwork, while in other cases informants may feel worried by the eventual departure of the fieldworker, since s/he is carrying friendships and confidences.[92] However, in my case, I felt worried by the responsibility of having those confidences, while my informants seemed to be unconcerned.[93] Also, although for a while after completing my research I continued to have friendships with people at St Z's, the strength of these declined as I became more involved in activities in Edinburgh and stopped visiting St Z's regularly. The distance between Edinburgh and St Z's made it

[89] The origin of this unpleasant phrase in colonial anthropology is clear.
[90] Wulff discusses her own emotional turmoil at ending her own fieldwork, and also cites Janet Siskind, who, for a while when conducting her fieldwork among native Americans in Peruvian Amazonia, felt that she wanted to remain in the village and Lila Abu-Lughod, who, when she was due to return from her second visit to the Bedouin community among whom she had conducted her fieldwork, was tempted to respond to their pleas to her to stay, including offering to provide financial support to help her to do so (Wulff op. cit., note 43).
[91] EE Evans-Pritchard (1956), 'Fieldwork and the empirical tradition,' in *Social Anthropology and Other Essays.* New York: Free Press, 79.
[92] Wulff, op. cit., note 43: 157.
[93] Again, perhaps this was because they were unaware of the implications of ethnographic research.

difficult to maintain these friendships, and in any case they were only partial friendships, since I always withheld a part of myself while doing my fieldwork.[94]

Thus, strong feelings arose for me around leaving the field, which highlighted my general feelings about St Z's and the people there. Particular issues concerning my feelings also arose for me in relation to sharing them with people in St Z's (as I have noted above), and also in relation to sharing my feelings about St Z's (and people there) with the academic community. Elizabeth Young describes her concern that in her fieldwork accounts she should not overplay the sensitive nature or the potential sensationalism of her research topic, nor dramatise her own experiences. She argues that first person accounts of sensitive research areas can leave the reader with the drama of the research experience, but without any methodological substance,[95] and comments that she does not want only to vent her own feelings, which she calls "baring [her] soul," but to ground them in a sociological context. I was less concerned in methodological or professional or sociological terms than Young – partly because of my explicit interest in the emotional aspect of knowledge – but some of the thoughts which Young expresses were also present for me, and of course have particular consequences for writing my fieldwork account.

Young was also concerned about how her audience might respond both to her topic in general and, specifically, to her attitudes towards the dying women she interviewed (whom she did not always like). Young and Lee point out that her concerns, and anxieties about how she might appear (for example, foolish or heartless), indicate that she had expectations about what she should feel as a social scientist studying this area,[96] which, in turn, indicate her sense of a "proper" sociological way to feel or to display feeling. Young and Lee suggest that this implies that the professions, including

[94] That is, I restrained myself from fully sharing all of my thoughts or feelings, because I did not want my thoughts and/or opinions to be made too explicit (although, of course, they were to some extent, and unavoidably, evident.

[95] Young and Lee, op. cit., note 9: 102.

[96] Young and Lee, op. cit., note 9: 109.

sociology, may be defined to some extent by their feeling rules.[97] The feeling rules for professionals such as nurses are both explicit and implicit, but for sociologists are largely implicit, such that one only finds out what they are if one breaks them.

The expectation of professional detachment and neutrality in much of social science, which implies the exclusion of the personal and/or emotional, related to the hierarchical dichotomy such that intellect/"rationality" is considered "superior" to and more scientific than feeling/"emotion," links to my discussion in the previous chapter and raises issues for representing fieldwork findings, including writing fieldwork accounts. I will now move on to explore some of these issues.

THINKING AND WRITING ABOUT ST Z'S

Analysis

As I discussed earlier in this chapter, it is generally accepted that, for ethnography, analysis is not a single event which occurs at the end of a period of data collection.[98] An ethnographer notices something in her/his fieldwork site, thinks about it, tries to make sense of it, returns to the situation and tests her/his new understanding in the light of new experience, then refines the interpretation accordingly. That is, the process of ethnography is iterative, dialectic, not linear. Ethnographers use themselves as "research instruments" both for collecting data and for testing their interpretations of data. This process is ongoing throughout the period of fieldwork (data collection); data are analysed and interpreted while being collected, not only after collection.[99] Although in this chapter I am discussing analysis after discussing my methodology, the two were interwoven, and arranging my discussion of them in this order is only a way of organising this chapter (it also mirrors my thesis structure, which, again, is a pragmatic

[97] Young and Lee, op. cit., note 9: 110.
[98] See, for example, Agar, op. cit., note 10: 9. Also see Spradley (op. cit., note 14), among many others.
[99] This iterative process of data collection and analysis was assisted by occasional supervision meetings during my fieldwork, which I found helpful in focusing ideas which were emerging from my findings, as well as reassuring me that my experiences and feelings were also data.

question of organisation, rather than a reflection of the process of its production). My analysis was iterative, and ongoing, to a greater or lesser extent, throughout my time in St Z's, although it did not end when my fieldwork ended, but continued after I had left St Z's.

The interaction between data collection and analysis is particularly evident in the interviews which I conducted. As I have noted, as my fieldwork progressed, I increasingly focused on interviewing workers who I felt might have views on and/or experiences of the spiritual aspects of care, and this focus developed through my analysis of my observations, as did my related decision not to interview patients. Taken as a whole, the interviews also illustrate the changes which occurred in me. They were conducted over the course of my fieldwork, which meant not only that by the time I conducted the later interviews I had more experience with interviewing, and so was more confident with the process, but also that I conducted these later interviews with people who by that time I knew fairly well, and I was close with some of them by then. So, by the time of the later interviews, not only had I reflected upon – analysed – some of the data I had collected through my fieldwork, but I also had more of a relationship with the people I was interviewing, and more shared knowledge and understanding.[100]

While doing my fieldwork I was also, to some extent, reflecting on the process of doing fieldwork itself, but this reflection also formed part of my analysis subsequent to finishing my fieldwork, including considering the interaction between analysis and fieldwork. As I have shown, Spradley's DRS Method served as a framework within which I learnt by doing my fieldwork. One of the chief things which I learnt was that I could have trusted myself much more. While I was doing my fieldwork I was very concerned to record details at the moment or close to the moment that they occurred, since I was anxious that I would forget things. In future, I would trust my ability to remember details from small prompts, and trust that I was more likely to remember than

[100] So, for example, by the time I interviewed SN16, I had begun to form ideas about what happened in St Z's, and in her interview she gave examples referring to particular patients whom I knew.

forget. I would also trust that what I was recording was of value, and that findings of value would emerge.[101]

My concern to record as much as possible meant that I effectively prioritised collecting data over reflecting on what I was observing. I now understand Spradley's comments on ethnography being a circular not a linear process, but they did not make sense to me while I was doing my fieldwork, and so I did not schedule time for reflecting on findings from my fieldwork in as systematic a way as I scheduled time for doing the fieldwork itself. In the future, I would more explicitly allocate time for reflecting on my fieldwork and would not be so centrally focused on *doing* the fieldwork (accumulating data).

Thus, a key thing which I learnt through doing my fieldwork was to allow plenty of time for analysis and reflection while I was collecting data. However, analysis also requires a degree of distance from fieldwork. Conducting analysis after fieldwork is complete makes it easier to perceive the overall picture of what happens in a situation, since one is not caught up with the detail of the day-to-day activities. In addition, being removed from the day-to-day events in a field site means that one is also removed from the people engaged in them.

This, in turn, links to another reason for conducting analysis after completing fieldwork. As I have described, I developed an attachment to the people I studied which was, like that commented on by other ethnographers, intense and personal. This intense and personal involvement means that some analysis is difficult to do when an ethnographer is still in the field and involved with the people there. It is thus inevitable that some parts of the analysis do not occur until after the fieldwork has been completed, when the necessary distance (physical and (therefore) emotional) has been reached.[102]

[101] As noted, my difficulty with believing this, and my uncertainty about what was data and whether I was collecting data correctly, were some of the reasons for my occasional feelings that I was "doing nothing."
[102] See also Savage (op. cit., note 40) on "closeness" and "distance" in nursing relationships, and nurses maintenance of professional detachment.

This was certainly so in my case, compounded by how painful I found it to leave St Z's and (as I commented above) to return to academia and so engage with the academic mode of thought. As I noted in the previous section, I felt protective towards the people in St Z's, extremely conscious of the (unavoidable) partiality of my account and its (also unavoidable) lack of full detail, and so very aware of the potential for negative/misleading interpretations of my findings. The result of this was that, particularly immediately after completing my fieldwork, I was reticent in sharing my findings with the academic community. I needed a certain amount of distance in time and space before I could feel comfortable talking and writing about people in St Z's. That is, I needed a sense of "connected detachment," continuing to care for people at St Z's, but feeling more distanced from them and less involved and identified with them.[103]

Thus, I conducted my analysis both while I was at St Z's ("in the field") and also after I had left St Z's, and there was some analysis which I *could* only do after I had left. Although I reflected on interview material as I proceeded through the interviews, my systematic analysis of my interviews was largely conducted after they had all been completed and transcribed, that is, after I had completed my fieldwork. In addition, my analysis of both participant observation and interviews continued while I was "writing-up," and writing formed part of the process of analysis; I thought by/through writing, attempting to make explicit the various kinds of knowledge which I gained through my fieldwork, and my analysis developed as I wrote.

Writing

Since the 1980s there has been a growth in the number of texts addressing the question of how to write ethnographies.[104] The stimulus to this growth is often attributed to the

[103] See Young and Lee's comments (op. cit., note 9) on the tension for the fieldworker between comfort, involvement and identification.

[104] As I have pointed out, there are far more such texts than texts on how to do fieldwork, and the question of how to write ethnography is far more evident in the literature than the question of how to do it.

"writing culture" texts which I mentioned earlier,[105] although, despite their ostensible sensitivity to how ethnographers wrote ethnographies, these texts themselves have been severely criticised for excluding women's voices.[106] This increased focus on writing ethnography means that it is difficult to claim any longer that ethnographic representation is innocent or neutral. The claim to objective, detached representation is no longer valid, and is revealed to be a convention like any other.[107]

Writing slightly later, John Van Maanen identified three narrative conventions for writing ethnographies: realist, confessional and impressionist,[108] and my writing probably fits the "realist" of these three conventions. However, I have not deliberately sought to write in such a way; I have not sought to be self-consciously realist, but attempted to write as clearly as I can, while maintaining an awareness of myself as the producer of this piece of knowledge, seeking to make myself continually present throughout this thesis, reflexively considering my own construction of knowledge, as well as that of people in St Z's.

As I have indicated, it is said that, ideally, ethnographic analysis is conducted iteratively, in interaction with data collection. However, for the reasons I have highlighted, this was not the case for all of my analysis. I conducted some analysis while I was at St Z's, and some immediately after finishing my fieldwork, but much of the analysis which I present in this thesis was not completed until some time later (in particular, my discussion of the metaphors of location and movement which people in St Z's used).

Harry Wolcott points out that the description and the analysis of a fieldwork account inter-relate: they interact dialectically, with the analysis helping to form the description, and the description providing the substance for analysis, so that each

---

[105] Clifford and Marcus, op. cit., note 3; Marcus and Fischer, op. cit., note 4.
[106] See, for example, Ruth Behar and Deborah Gordon (eds.) (1995), *Women Writing Culture*. Berkeley, Los Angeles, London: University of California Press.
[107] Again, this links to social constructivist arguments, as noted previously.
[108] John Van Maanen (1988), *Tales of the Field: On Writing Ethnography*. Chicago and London: University of Chicago Press.

informs the other.[109] Writing one, then returning to the other, serves to maintain the central focus while reducing extraneous detail; as Wolcott says, "we carry in our heads far more of our studies than we ever commit to print."[110] That is, although writing is also analysis, analysis is not only what is written.

I conducted much of my analysis while "writing-up", and writing my description and analysis interactively has been a struggle, and time-consuming, for me. In the early days of my research I had rather ambitious plans to write my thesis in a way which would convey the complexity of the interaction between theory, method, empirical findings and analysis, but I abandoned this ambition when the current structure of my thesis proved to be sufficiently time-consuming. I would have found it impossible to write in this complex way while also doing my fieldwork – as I have already noted, I had not allowed enough time during my fieldwork for writing up my fieldnotes, let alone for analysis, let alone for writing my fieldwork account (description) in interaction with analysis. Nor was my understanding such that I would have been *able* to begin writing my analysis while doing my fieldwork. The process I followed, while it was reflective throughout, was much more linear than this: data collection, analysis, writing-up. It was only my writing-up that was fully iterative.

My writing was shaped to some extent in relation to the question of audience: the question of the people for whom I am trying to make my knowledge explicit. Although my work is multi-disciplinary, drawing on various fields, including social studies of STM, feminist philosophies of knowledge, palliative care, studies of death and dying, and nursing studies, it is impossible to write for all these multiple possible audiences at once,[111] let alone to adequately address all these bodies of literature. I therefore had to identify my primary audience, and increasingly realised that, in a way, this had to be myself, within, and as an example of, an audience from social studies of STM, since that

[109] Harry F Wolcott (1990), *Writing Up Qualitative Research.* Newbury Park, London, New Delhi: Sage: 50.
[110] Wolcott, op. cit., note 100: 49. Also see Jackson, op. cit., note 12.
[111] I can address each audience more directly and specifically via shorter, targeted papers.

is how I came to this project, and because I had multiple, interwoven personal motivations, both emotional and intellectual, for embarking on this project.

Thus, writing this thesis has been a process of reaching and clarifying my understanding of my empirical findings from St Z's, theoretical issues drawn primarily from social studies of STM, and the relationships between these. That is, through my research and my writing about it I am trying to understand the theoretical understandings which I have drawn from the field of social studies of STM, and also trying to understand the things and events which I observed and/or in which I participated in St Z's in terms of those theoretical understandings. This includes exploring the relationships between what people do and what they think, and including trying to make sense of my own thoughts, feelings, and experiences before, during and after the time I spent in St Z's.

My theoretical understandings of knowledge as socially situated imply that I have to take a reflexive position towards my own production of this thesis as a piece of knowledge. Situating the production of knowledge means asking where the knowledge comes from. Who has produced it? Who and/or what for? As I outlined in the previous chapter, while I was studying for my MSc, and during my first year reading for my PhD, I developed a certain level of understanding, my own perception, of the meaning and consequences of the argument that knowledge is socially and culturally produced. During and after my fieldwork, I identified various findings as significant, and then, with these findings in mind, I returned to the theoretical literature, reading it this time from a perspective which included the knowledge, tacit and explicit, which I had gained from being in St Z's. In turn, my reading of the theoretical literature developed my understanding of why, out of all the things in which I participated or which I observed, I had identified certain events as particularly significant.

This profoundly iterative process made it difficult for me to start writing. Although I knew my starting point: my research question and the theoretical framework in which I was interested, my empirical findings had consequences for which particular

aspects of that theoretical framework were relevant. In turn, theoretical insights highlighted particular aspects of my findings, and why these aspects had struck me as important. The interaction between theory and empirical findings meant that I wrote chapters two, three, four and five in interaction with each other. I first wrote the previous chapter and this one (that is, chapters two and three) in outline. Next, I outlined my two empirical chapters (chapters four and five). I then returned to this chapter, then to chapter two, and then to the two empirical chapters. I continued developing and writing these four chapters in alternation and dialogue with each other.

That is, I began by identifying the broad theoretical and methodological issues which interested me, and which I thought might bear on my fieldwork. Next, while I was doing my fieldwork, writing up my fieldnotes, and writing my empirical chapters, I identified the empirical issues which seemed important to me, in the light of the broad theoretical and methodological themes which I had identified. Reflecting on these empirical issues highlighted those aspects of the theoretical and methodological issues I had identified which were particularly relevant to the empirical issues I had identified. I developed these two chapters accordingly, and writing further about these theoretical and methodological issues illuminated my empirical findings and fed back into further thinking and writing about these.[112]

This protracted process in the end, however, facilitated my choice of which tense to use for writing my ethnographic account. As Anna Tsing comments, there is "considerable intellectual and political significance" to whether an ethnographer writes an ethnographic account in the "ethnographic present" or the historical past.[113] She argues that what she calls the ethnographic present can represent culture as a coherent and persistent whole, a timeless scene of action, so using the present tense can turn

[112] I engaged in the same process of writing the theoretical in alternation and interaction with the empirical within a chapter which was originally part of this thesis in which I considered the relationship between ethics, spirituality and care in St Z's (owing to word limits, I then had to cut this chapter from my thesis, although part of it was subsequently published (Vivat, op. cit., note 34) and has therefore returned as appendix VI).

ethnographic subjects into exotic creatures, who exist outside the time of civilised history.[114] Conversely, using the historical past suggests not only that people *have* history, but that they *are* history, that what they do is over and finished; and this is part of the reason why early 20th-century ethnographers turned to the present tense. Tsing chooses to use both tenses, saying that she is in part aiming to disrupt such problematic assumptions. At times, therefore, she uses the past tense in order to displace accounts of timeless systems; at other times the present tense, so as to keep open the possibilities of what might happen.[115]

The political aspects of these issues are less pressing for people doing ethnography "at home," but nevertheless the decision of which tense to use was not straightforward for me when I began writing, when I still felt involved with St Z's, and so felt that what I was describing was (still) ongoing. However, even at that time it seemed to me that it was important to convey the sense that my ethnography is (only) about a particular time, place, and group of people, particularly because of the significant changes which began to occur in St Z's towards the end of my fieldwork. Although many of the people who were working in St Z's when I conducted my fieldwork are still there now, these changes make it especially clear that St Z's is not the same place now as when I conducted my fieldwork. Further, none of the patients who were there when I conducted my fieldwork are still alive. The chapters on which I report on my fieldwork findings are therefore written in the past tense.

Names and pseudonyms

Obviously, for reasons of confidentiality, I have not used the real name of anyone in St Z's. In order to make it clear whether I am referring to patients or to other people in St Z's, I have given all the patients pseudonyms and given workers and volunteers a code

[113] Anna Lowenhaupt Tsing (1993), *In the Realm of the Diamond Queen.* Princeton, NJ: Princeton University Press: xiv-xv.
[114] See also Strathern, op. cit., note 28.
[115] Tsing, op. cit., note 113.

which is a combination of letters and numbers. The letters indicate their main roles in St Z's, as follows: AN (auxiliary nurse), SN (staff nurse), Dr (doctor), Sr (sister), HCC (home care coordinator), DCC (day care coordinator), PT (physiotherapist), SW (social worker) and Vol (volunteer). I numbered my interviews sequentially as I conducted them, and have assigned the number of the interview to each of my interviewees. So, workers with the numbers 1-24 were interviewed by me in that order (which also means that the numbers indicate the point during my research when I interviewed that person). So, for example, SN 17 is a staff nurse who was my 17th interviewee. I have assigned numbers to other workers arbitrarily, as I discuss them in the thesis. When I discuss the views or actions of a particular worker or volunteer in detail I give more details of each person, not enough to enable their identification, but sufficient to convey a sense of their characteristics.[116] This information can also be found in appendix IV.

This system of codes and pseudonyms is not ideal, since names were important in the hospice for several reasons. It is often the case in allopathic medical organisations (similarly to other hierarchical organisations) that people lower down the hierarchy are named in a less formal manner than those higher up. So, nurses, workers in "PAMs" ("professions allied to medicine," such as occupational therapy or physiotherapy), and also patients are commonly addressed by their first names, while Dr plus surname (for example, Dr Smith) is used for doctors. A similar situation existed in St Z's, where workers used Dr plus surname to address and refer to both doctors.[117] In addition, the priests and nuns were addressed and referred to as Father plus first name, or Sister plus first name (for example, Father Mark or Sister Mary). First names alone were used for all other workers, and people in St Z's frequently greeted one another using their first names, that is, by saying not just "Hello," but "Hello, Bella." People also often used

[116] Nevertheless, some people could still be identifiable to colleagues, since they were the only person in a particular professional role, such as the medical director, the new medical consultant, the matron and deputy matron. People's professional roles are important for my analysis, and so cannot be concealed. However, while anybody associated with St Z's could identify these individuals, it would be more difficult for anyone not directly involved. Further, the time of my fieldwork is now relatively distant.

each other's first names when conversing, for example, "it's different, isn't it, Bella?" not (just) "it's different, isn't it?" (examples drawn from the transcripts I cite from my interview with SN 17 in chapter five).[118]

Despite this use of first names for most workers, however, people in St Z's were still aware of the professional roles of each worker, either because of the uniform they wore or (for those who did not wear a uniform, such as the social workers) simply because they were recognised within the hospice. I therefore decided to use codes so as to identify workers on the basis of their professional role, a characteristic which was evident to me and to other people in St Z's even while using workers' first names, but which a (pseudonymous) first name would not convey to the reader of this text. The use of codes also has a distancing effect and thus highlights that I have constructed a version of St Z's in this thesis. Using codes is a way by which I can maintain the awareness that this is a constructed text, and resist the thesis slipping into story mode, with the comfort of having "characters," which can then seem more "real."

In order to distinguish between patients, volunteers and workers (again, a distinction which was evident to people in St Z's but would not be evident to readers), I chose to use pseudonyms for patients. My choice of pseudonyms was complicated by my awareness that in the West of Scotland (where religious affiliation is an important issue for many people), people are often able to identify other people's religion on the basis of their name, often both first name and surname. St Z's was a Catholic hospice in a largely Protestant town, so people's religious affiliations were even more significant there than elsewhere in the West of Scotland. I will return to this point in the next chapter, but here I will comment that I do not have the sensitivity to the religious

[117] In the next chapter I briefly discuss the discomfort of workers when Dr 21, the new medical consultant, asked them to call him by his first name, and their response, which was to call him "Dr Peter."

[118] This frequent use of first names was not unique to St Z's, however; I also noticed this manner of talking in the town where St Z's was situated, and have also noticed it at other times and in other situations, such as when I previously lived in Glasgow, when working as a volunteer with various organisations in Edinburgh, and also with some London working class friends of mine. It seems to me that this way of speaking is possibly class-related, since it is unusual in many other groups of which I am part, and is

affiliations signified by particular names in the West of Scotland, so I cannot be sure whether the pseudonyms I have chosen for patients convey the appropriate religious affiliations.

Some time after leaving St Z's, I discussed the question of pseudonyms with a friend of mine, who told me that she had asked the people with whom she had conducted her research to choose their own pseudonyms. I did not think of this possibility while I was conducting my fieldwork, and some workers left the hospice, and some patients died, during my fieldwork and after I left St Z's. It was therefore impossible for me to ask all the people I had studied to choose their own pseudonyms, and so I decided to keep to my own, albeit problematic, choice.

Discourse analysis: interviews

As I have shown in this chapter, I gathered various material during my fieldwork in St Z's, and I have analysed these various kinds of material in different ways, using methods which are appropriate for the particular data. So, I drew on ethnographic techniques to analyse my fieldnotes, including my notes from conversations I had with people in various parts of St Z's, and notes on the interactions (including talk) between people in the weekly case conferences. Conversely, my analysis of the taped interviews I conducted with workers draws largely on techniques from discourse analysis.

From the discourse analytic perspective, talk is action, since it involves interaction between people; talk is not (simply) communication, in the sense of a one way transmission of facts/opinions from one person to another; instead, talk is a social practice and the meanings of talk are intersubjectively constituted.[119] As Sue Wilkinson and Celia Kitzinger point out, discourse analysis shares common ground with other critical approaches in social science, such as social constructionism and critical

notably *not* something which happens (or only rarely) between academics around many universities, for example, the University of Edinburgh.

[119] Derek Edwards (1997), *Discourse and Cognition.* London, Thousand Oaks, New Delhi: Sage: 108.

ethnography.[120] Thus there is common ground between this analytic approach, my theoretical framework and my methodology. Further, significant work focusing on the language of STM has been done in social studies of STM.[121]

From the discourse analysis perspective, the language people use to talk about experience in a sense constructs the social world as well as describing it.[122] The discourses and practices available to people in a particular social, cultural and historical location shape how they conceptualise their beliefs and experiences, and so shape what they are able to say. Thus, particular historically, culturally and socially located discursive practices constitute people's understandings and experiences.

Derek Edwards argues that people design their descriptions for the actions which they want them (their descriptions) to perform in interaction with others; that is, description (talk) is action in that people use it to construct one particular sense of events rather than another sense; people design their descriptions so that particular inferences will be drawn from them.[123] Participants enlist actions' visibility such that they will be taken for what they appear to be,[124] that is, people produce actions with regard to how they will be perceived by others. This does not necessarily mean deceptiveness or insincerity (although it can do), but it does mean that talk is geared to socially accountable interaction, actions which need to be seen to be done.[125]

Edwards claims that people adopt different ways of talking in order to package the content of their talk variously as "new/news,"[126] "fact," "common/shared

---

[120] Sue Wilkinson and Celia Kitzinger (1995), 'Introduction,' pp. 1-9 in Wilkinson, S and C Kitzinger (eds.), *Feminism and Discourse: Psychological Perspectives*. London, Thousand Oaks, New Delhi: Sage. Also see Jonathan Potter (1996), *Representing Reality: Discourse, Rhetoric and Social Construction*. London, Thousand Oaks, New Delhi: Sage, and Michael Lynch (1993), *Scientific Practice and Ordinary Action: Ethnomethodology and Social Studies of Science*. Cambridge: Cambridge University Press.

[121] See for example Michael Mulkay (1985), *The Word and the World: Explorations in the Form of Sociological Analysis*. London: Allen and Unwin.

[122] Wilkinson and Kitzinger, op. cit., note 120: 3.

[123] Edwards, op. cit., note 119: 98.

[124] Harvey Sacks (1992; edited by Gail Jefferson), *Lectures on Conversation*. Oxford: Blackwell: 254.

[125] Edwards, op. cit., note 119: 99.

[126] Edwards, op. cit., note 119: 122.

knowledge,"[127] and so on. Thus, people's descriptions construct the nature of events.[128] This is not to say that events are not "real," but rather to say that language contributes to their reality, which is in large part constructed by the symbolic meanings people attach to their experiences and perceptions, and by the way in which people interpret social reality. That is, language is a medium by which people actively construct experience; it does not simply reflect a pre-existing reality, nor, contrary to the communication model for talk, is it a transparent medium for conveying unchanging "facts" or "accurate" definitions.[129]

Because of this, focusing only on the content of talk and not exploring the manner of talking misses much that is important about talk. As Wood and Kroger point out, however, the detail of how talk is organised cannot be explored while one is listening and/or participating in conversation. In order to identify this detail, discourse needs to be slowed down, and this is the purpose of transcription. A transcript is not a literal rendering of discourse, but it can display some of the features of discourse. Since the important features of discourse cannot be specified in advance, it is critical to include as much detail as possible of the discourse, so as to avoid oversimplification or unacknowledged interpretation (if details are omitted, this means that they have been (consciously or otherwise) interpreted as irrelevant).[130] A transcript therefore needs to be as comprehensive as possible, and transcription is not only a record on paper but a theoretical and analytical activity.[131]

Many discourse analysts, including Wood and Kroger, use versions of Gail Jefferson's system for notating transcripts, which, to a greater or lesser extent, represent talk phonologically (that is, including non-word sounds and emphasis), rather than

---

[127] Edwards, op. cit., note 119: 117.
[128] Edwards, op. cit., note 119: 124.
[129] Celia Kitzinger and Alison Thomas (1995), 'Sexual harassment: a discursive approach,' pp. 32-48 in Wilkinson, S and C Kitzinger (eds.), *Feminism and Discourse: Psychological Perspectives*. London, Thousand Oaks and New Delhi: Sage: 35.
[130] Linda A Wood and Rolf O Kroger (2000), *Doing Discourse Analysis: Methods for Studying Action in Talk and Text*. Thousand Oaks, London and New Delhi: Sage: 82.
[131] Wood and Kroger, op. cit., note 130: 84.

orthographically (that is, using standardised spellings and punctuation).[132] I have also adapted Jefferson's system, and my own version is included as appendix V.

Since discourse analysis focuses on the detail of talk, that is, not only on *what* is said but also *how* it is said, I used discourse analysis only to analyse the taped interviews which I conducted. I did not use a discourse analytic approach to analyse other talk in St Z's which I was part of or a witness to, because I did not record this latter talk in the same kind of detail as I was able to do in my transcripts of interviews. That is, although I noted the *content* of other remarks and comments made by workers in St Z's, and at times, such as in case conferences, I was able to record these verbatim, I was unable to record the detail of the *manner* in which people said them (that is, features such as intonation, pauses and repetitions).[133]

Although interviews are not "natural talk," which is preferable for discourse analysis, Edwards argues that "[a]ny interactional phenomenon can be *naturalized* by *treating it as* natural."[134] Edwards argues that meanings are interactionally accomplished; that meaning is local, specific, and conditional on the sequential organisation of the interaction (talk); intentionality is accomplished and established in interactions, not revealed or reiterated.[135] So, if one focuses on how people talk, not only on the content of what they say, interviews can be treated as a particular sort of talk-in-interaction, examining the interactions between interviewer and interviewee, rather than treating only interviewees' responses as "data."[136]

Wood and Kroger say that, if time permits, the analyst should do the transcription, which helps her/him to notice patterns and recurring details in the

---

[132] Wood and Kroger, op. cit., note 130: 83. See Gail Jefferson (1984), 'On the organization of laughter in talk about troubles,' in JM Atkinson and J Heritage (eds.), *Structures of Social Action: Studies in Conversation Analysis*. Cambridge: Cambridge University Press: 346-69.

[133] There is an interesting echo here of the distinction between manner and content of spiritual aspects of care which I make later in this thesis.

[134] Edwards, op. cit., note 119: 89.

[135] Edwards, op. cit., note 119: 107.

[136] Edwards, op. cit., note 119: 89.

discourse.[137] They say that the analyst should listen to the recording, and, once a transcript has been produced, read it several times, and only then begin to move to identifying key features.[138] George Psathas suggests that the analyst begin with "unmotivated looking," rather than looking in the data for a predetermined set of analytic categories.[139]

I transcribed my interviews over a period of time, some of the earlier ones while I was still doing my fieldwork, others after I had left St Z's. Transcription was an interesting experience: the intonation and vocal patterns of some people were particularly noticeable, but impossible to transcribe in detail; I could only note that there were such patterns. However, these patterns helped me to notice repeated phrases, which perhaps I would not have noticed if someone else had done the transcribing. One feature which I noticed through, and early on in, doing the transcriptions, and subsequently through looking at the transcripts, was how many people struggled to talk about spirituality and spiritual aspects of care, especially the reiterations of "I don't know." Although my interest in the spiritual aspects of care meant that I was already focusing particularly on the parts of the interviews where we discussed this, it was Psathas' "unmotivated looking" which enabled me to notice workers' repeated use of "I don't know" and "you know," and also to notice another striking feature of their talk: their use of metaphors.

Wood and Kroger discuss the various ways in which discourse analysts have explored metaphors,[140] and emphasise that metaphors do not have to be unusual or striking to be worthy of analysis, but that, especially if they are *not* unusual, they are frequently not noticed, precisely because they are so pervasive in all forms of discourse, including the academic. Thus, I had read my interview transcripts several times before I

---

[137] Wood and Kroger, op. cit., note 130: 86. See their comments, as noted above, that transcribing is a theoretical and analytical activity.7

[138] Wood and Kroger, op. cit., note 130: 87.

[139] George Psathas (1995), *Conversation Analysis: The Study of Talk-in-Interaction.* London: Sage.

began to notice the pervasiveness of metaphors of location and movement in workers' talk, but once I had begun to notice these metaphors they seemed extremely significant to me.[141] Further, once I had noticed workers' use of metaphor in my interview transcripts, this also became evident to me in my notes from case conferences. So my analysis of interviews interacted with and fed into my analysis of data from my participant observation.

As I noted above, when I began my fieldwork I intended to interview patients about issues relating to the spiritual aspects of care, and I did not anticipate that I would feel unable to do this. However, as my fieldwork progressed, I gradually felt (for the reasons I have noted above) that I could not interview patients (or talk to them in any great detail) about the spiritual aspects of care in St Z's. Patients' voices are therefore largely absent in my discussion of the spiritual aspects of care, and this was not my original intention. Now, looking back, my regret at the absence of patients' voices is greater than my ethical reservations (again, this is a function of my increased distance from the people in St Z's/my fieldwork).

It has also been suggested to me that, even if I did not feel that there was anyone in St Z's who would be able to continue the kind of conversation I had been participating in with particular patients, perhaps a partial conversation with me about spiritual issues would have been better than no conversation at all.[142] However, conversation is not the same as an interview (conversation is less formal/intense, less probing). Further, if, later on in my fieldwork, I had returned to my original plan of interviewing patients, this would have been a distortion since it would have meant that those patients whom I had

---

[140] Wood and Kroger, op. cit., note 130: 104-5 and chapter 3. Also see Edwards (op. cit., note 119) for a general discussion of metaphor, and Lakoff and Johnson's much cited work (George Lakoff and Mark Johnson (1980), *Metaphors We Live By*. Chicago and London: University of Chicago Press.)

[141] It is possible that if people in St Z's had used UP instead of DOWN metaphors, their meaning would have been equally self-evident to me, but I feel that if they had used UP metaphors I would have noticed and questioned these metaphors more than I initially noticed their DOWN metaphors, since DOWN metaphors fit with my own metaphorical understanding.

[142] Personal communication from a palliative care nurse/counsellor.

known earlier and who had died would have been excluded, which would also have reinforced my sense of loss relating to these patients.

CONCLUSION

In this chapter I have outlined my approach to doing my fieldwork and representing my findings, and have addressed some of the complexities underlying what I will be presenting in the next chapters. I will now move on to discuss the key points which I identified from my fieldwork. In the next chapter (chapter four) I discuss the three main places where patients came in St Z's: day care and the two wards: St E's and St P's. The material in this chapter is drawn from my fieldnotes. In the following chapter (chapter five), I will focus on the spiritual aspects of care, drawing mainly on material from my (taped) interviews with workers.

- 4 -

LOCATION AND MOVEMENT IN ST Z'S

INTRODUCTION

St Z's patients came to one of three places in St Z's: day care, the elderly care ward ("St E's"), or the palliative care ward ("St P's"). Some patients came to all three of these places at different times, while others might only ever come to one. In this chapter I shall consider these three parts of St Z's, and the general features which I want to highlight about St Z's, drawing mainly on material from my participant observation. I will focus particularly on day care and the palliative care ward, since palliative care patients mainly came to these parts of St Z's.[1]

After I had been doing my fieldwork for a while, I increasingly began to think that the three parts of St Z's where patients came were quite distinct, and so to think that in many ways it did not make sense to think of St Z's as a single place. There were different "kinds" of patients in each part of St Z's, and, linked to this (since different "kinds" of patients were perceived as having different needs), activities and workers' practices differed between these places, with a particular combination of workers in each place. Volunteers worked in some parts of St Z's but not in others, and the health care professionals in each place occupied particular professional roles. Workers in each part of St Z's perceived themselves as having particular sets of responsibilities, associated with their professional or voluntary role and the particular place in St Z's where they were located. Thus, day care activities were highly structured, and workers in day care aimed to keep patients active and busy, so that they were distracted from their illness. St E's was also a highly structured environment, while St P's was less busy, with less routine, and the nurses there had more time to give individual attention to patients.

---

[1] The limited space I have available means that I have to select those issues which are most relevant to my focus of interest, and I suggest that issues relating to death and dying were most present for palliative care patients. I therefore consider the elderly care ward briefly, and mainly in relation/contrast to the palliative care ward. Further, although interesting issues arose in the drop-in for bereaved children, I do not consider them in this thesis, since they do not directly relate to my central argument.

However, these differences between the different parts of St Z's linked (paradoxically, it might seem) to similarities between them. One similarity was precisely the division of labour between workers which was evident in the differences between the parts of St Z's. Workers' particular roles and the combinations of professionals and volunteers in each place were associated with the different "kinds" of patients in each place. In this way, the division of labour between workers produced and reproduced the differences between the parts of St Z's.

These differences also linked to a second similarity across St Z's: the significance which people across St Z's attached to patients' movement between and location within each of these three places. The perception that there were differences between these three parts of St Z's was not only mine, but also that of workers and patients, and their (implicit) association of each place in St Z's with different "kinds" of patients gave significance to patients' movement and location within and between spaces.

The (non-explicit) distinction between different "kinds" of patients and the allocation of patients to particular spaces in St Z's were shaped by patients' physical health. Pivotally, patients' physical location and movement related (again, non-explicitly) to workers' perceptions of how soon particular patients were likely to die. This was the basis for decisions concerning where patients were physically located in St Z's, and for whether they moved between spaces, and, if so, from and to where. In this way, patients' physical location and movement was associated, by both workers and patients, with their physical health: their perceived – metaphorical – location relative to death, that is, their metaphorical proximity ("closeness") to death. Thus, workers distinguished between the various aspects of patients' health, and effectively prioritised the physical. Associated with this, care was fragmented, with patients' physical care also primary. So, in effect, a hierarchy existed between these aspects of health and care, associated with the division of labour between members of the "multi-disciplinary team."

Amplifying the importance which people in St Z's attached to patients' physical location and movement in St Z's, workers across St Z's used metaphors of

movement to speak about their perceptions of how likely particular patients were to die. Workers sought to predict and anticipate the deaths of some patients, in part because of the importance of this in where they located patients. People across St Z's indicated that they considered that particular patients were likely to die by talking about them as "going down" or "going downhill," that is, as, metaphorically, going somewhere else (a similar physical metaphor to that which they used for patients' emotional states, speaking of unhappy or depressed people as being "down").

Thus, workers constructed death as somewhere else – downwards, and patients' location and movement in St Z's related to how far "down" workers thought they were, or workers' perceptions of how likely patients were to begin moving "down." Particular places in St Z's were allocated to patients who were perceived as more likely to die, and so workers (and patients) perceived different places in St Z's as more or less appropriate for patients' deaths.

Another feature common to much of St Z's was a particular *absence* of talk between workers and patients. Although workers spoke amongst themselves about patients' deaths and dying, they generally avoided speaking with patients in public about death and dying, although workers in different places avoided this in different ways. Thus, talk about death and dying was also located in particular places (private spaces) in St Z's, and this reinforced the construction of death and dying as occurring in some places and not in others.

A BRIEF OVERVIEW OF ST Z'S

As noted in the previous chapter, St Z's was a Catholic organisation, named after a saint ("St Z"), as were both wards ("St E" and "St P"). However, most people in the town were Protestant, as was evident in the numerous Church of Scotland churches in the town, and also apparent in that many pubs had Protestant-associated names, such as "King William III."[2] As is often the case in the west of Scotland, people in St

[2] William, the Dutch Protestant Prince of Orange, became King William III at the request of Parliament after James II, a Roman Catholic descended from the Scottish James I, lost the throne of England in the so-called "Glorious Revolution" of 1688. James allied himself with France and

Z's were strongly aware of people's religious affiliations and differences (so, for example, a nurse told me that she was in a "mixed marriage," by which she meant that she was Catholic and her husband was Protestant), and were very conscious that the town was "Protestant," in contrast to the nearby town, which had a majority Catholic population. Several people told me that in the early days when the Irish order of nuns which founded St Z's was seeking funds, initially to build the hospice itself, and later for hospice activities, people had refused to give money in street collections because St Z's was a Catholic organisation. When the hospice was first established there had also been difficulties with patient admissions and referrals. A friend of mine from medical school, who had worked as a neurologist in the local hospital, told me that he had met patients who refused to be sent to the hospice because they were afraid that the "Fenian" nuns would try to convert them to Catholicism on their death beds.[3]

However, although patients in St Z's were conscious of their own and others' religious affiliations, they were seldom explicit about this. Hence the rare occasions on which some patients expressed this awareness were noteworthy. One such patient was Jimmy D,[4] a (Catholic) day care patient who was not always able to control what

---

travelled to Ireland, where the lord deputy was a Catholic loyal to him. Subsequently, various battles took place between Catholics and Protestants in Ireland, until the crucial battle on the River Boyne on July 1st, 1690, at which William's army defeated the Jacobites, and after which James fled to France. These events also connect to the complex political and religious relationship between Ireland and the west of Scotland, including the settling of many Scottish Protestants in Ireland during the "plantation." Hence, the Protestant-Catholic tension in the north of Ireland is mirrored in the west of Scotland. In both areas, the Protestant "Orange Order" celebrates the victory of "King Billy" at the "Battle of the Boyne" every July (although on the 12th, not the 1st, of July, since in 1752 the calendar was changed from the Julian to the Gregorian, adding 11 days) (Liz Curtis (1984), *Nothing But the Same Old Story: The Roots of Anti-Irish Racism*. London: Information on Ireland).

[3] These issues of course raise the question of why the nuns had decided to establish St Z's in this particular town rather than elsewhere; Sr B (an elderly nun who worked as a receptionist for the hospice) told me that they had felt "called" to build the hospice there.

[4] See my discussion in the previous chapter of my use of pseudonyms. In particular, note that I distinguish between patients and workers (that is, both volunteers and waged staff) by using pseudonyms for patients and codes for workers (see appendix IV for a recapitulation of these codes and brief biographical notes on workers). I also indicate the names of the hospice and its wards by using letters to stand for the saints' names: St Z's for the hospice, St E's for the elderly care ward, and St P's for the palliative care ward. An additional language-related issue is that of how to refer to those people with terminal illnesses who came to St Z's. Neither "patients" nor "clients" is an entirely satisfactory term, and "people" is not always sufficiently clear. However, workers called these people patients, so, when clarity is needed, I generally do the same, although this obviously raises questions of terminology. As a final note on terminology: at times I refer to patients' "disease." I am not using this

he said,[5] and who periodically exclaimed about "Tory" and/or "Orange" "bastards."[6] Another patient who explicitly commented on religious affiliations was Bill, a long-term palliative care patient who could be confused at times. One day in early May I was talking with Bill in the corridor alongside the garden, where he was sitting in his wheelchair and I was sitting on a bench alongside him. We had talked about the different colours of the wallflowers in the garden, how hard the gardener worked, and the gardener's dog, when, for no apparent reason (since this was two months before his birthday), Bill said: "I don't know if I should tell you this, but I'm not a Catholic, I'm a Protestant."

me: "That's fine, I'm not a Catholic either."

Bill: "It's my birthday on the 12th of July and me and my wife are worried about it, we don't want them to think we're celebrating something else;[7] maybe we should keep it quiet."

me: "I'm sure they know already, and I'm sure they don't think any differently of you because of it."

Bill: "Don't tell anyone, will you? That PT 9, she's very attached to her religion. Protestants and Catholics hate each other."

Bill had a close relationship with PT 9, but this did not seem to affect his concern. People's sensitivity to each other's religious affiliation, associated with most people's silence on this point, obviously had consequences for spiritual care, and I return to it in the next chapter.

St Z's was situated just to the north of the town's main shopping centre, which was spread across several small hills. I usually arrived in the town by train and walked to St Z's through the shopping centre, where I often met people I knew from St Z's (usually volunteers, but occasionally workers, and also (less frequently)

---

word as a euphemism for "cancer," but rather seeking to account for those hospice patients (albeit a small number) who had MND (motor neurone disease) rather than cancer.

[5] Workers ascribed Jimmy D's limited control over what he said either to brain metastases or to head trauma from a road accident which he had had a few years before.

[6] The workers were extremely uncomfortable with his swearing and tended to ignore or laugh at it.

[7] That is, the Battle of the Boyne. In the event, Bill was unwell around the time of his birthday, so the problem of the celebration did not arise.

relatives of hospice patients). The local area was poor; Rev 19[8] told me that the town was 93% APT (Area of Priority Treatment – a term used by the Church of Scotland) and also a UPA (Urban Priority Area – a government term). The shopping centre reflected this: the shops were mostly charity shops and cheaper chain stores, and there was also a boarded-up supermarket, which had been replaced by a new one on the outskirts of the town. At all times of the day there were many adults about in the town, including many young women with babies in pushchairs.[9]

St Z's was situated towards the top of a low hill between the shopping centre and a small park. As I noted in the previous chapter, St Z's was built into the side of the hill, and so the building was partly single storey and partly on two storeys. That part of the building where the wards were was single storey, and extended westwards to become the first floor of the two-storeyed part of the building, which was mostly taken up by the nuns' bedrooms. The lower level of the hospice was therefore smaller than the upper level, and it was windowless on the side against the hill. The store rooms and staff changing rooms were on this side of the lower level, with the kitchen, the staff rest room and staff dining room, day care, and the lower floor of the convent on the side facing out from the hillside.[10] A road ran from the main entrance around the side of the convent to the rear entrance on the lower floor at the back of the building, where the kitchens and storerooms were situated. The original (pre-conversion) entrance to day care was through a fenced garden alongside this rear entrance.[11]

The wards in St Z's formed three sides around a central garden of paved areas and formal flower beds, with a fountain and fishpond in the middle, and a few wooden benches scattered between the flower beds. St E's was on two sides of the garden, and St P's on the third. The fourth side of the garden was a corridor, which

[8] The local Church of Scotland minister, who conducted a weekly ecumenical service in the chapel at St Z's.

[9] The youth of mothers in this area was also evident in that I met several women visiting their mothers on St E's who were themselves grandmothers.

[10] See the diagram of the general layout of the building in the previous chapter.

[11] As I said in the previous chapter, my fieldwork coincided with a period of change and development of St Z's, including the building of a new convent and the conversion of the original convent to offices and an enlarged space for day care.

led from the reception area to St P's. On one side of this corridor were windows onto the garden, and on the other side were a large meeting hall, the chapel and various offices.

When I began my fieldwork, St E's (the bigger ward, with 22 beds) was the elderly care ward and St P's (the smaller ward, with room for 10 patients, occasionally 11) was the palliative care ward. Towards the end of my fieldwork managers began to use beds on St E's which became free (as patients died) for palliative care patients. The aim was that eventually the sizes of the elderly and palliative care wards would be reversed, such that St E's would finally be the palliative care ward and St P's the elderly care ward (and so St Z's would eventually have about twice as many palliative care patients as elderly care patients).

The main entrance to St Z's led into the reception area via a small glass-panelled space within which stood a painted wooden statue of St Z (the patron saint of the hospice) and several large potted plants. During the day two lay receptionists (paid workers) were behind the reception desk, greeting visitors and doing various administrative tasks (writing letters, filing, photocopying, and so on) alongside a nun, Sr B, who mainly operated the switchboard. In the evenings the reception was staffed by volunteers.

The tea bar opened off the reception area, as did, prior to the conversion, the finance office and the matron's office. The upper floor of the original convent could also be reached from here. During the daytime, therefore, the reception area was usually busy with workers, patients' relatives, and occasionally patients, who were going to and from the wards, chapel, offices and tea bar. Occasionally nuns passed through this area when going to and from the convent, although they usually used the convent's side entrance.

There were two sofas near the main entrance to St Z's, and people sometimes sat and talked on these, usually people from the town who were waiting to be picked up after mass or other events, or occasionally patients who were going on or returning from day trips. Bill and another patient, Tom, both of whom were living in

single rooms on St E's,[12] sat in the reception area almost every day in their wheelchairs, looking out through the windows. Although they seldom spoke with anyone when they sat here, Tom said that he enjoyed "all the goings on."

The tea bar was run by a group of volunteers, who were all middle-aged or older, and all female, as were the majority of staff and volunteers in St Z's. The male workers were: a few volunteer drivers; one (later two) palliative care consultant/s; two local GPs; several local priests; two male nurses on the elderly care ward; and two maintenance men. Directly inside the entrance to the tea bar were several small tables and chairs, and patients and/or their relatives usually sat here. Immediately to the right of the door was a large fridge, beyond which was a low table and a padded bench, where members of staff tended to sit.

Different spaces, different places

As I noted in the previous chapter, during my fieldwork a new convent was built in the grounds of St Z's, and the existing building was converted for use solely as a hospice. When I began my fieldwork, however, St Z's was a single building, containing both the hospice and the convent, although the original convent was distinct from the rest of the building, being self-contained, with its own, separate entrance. But I also felt that the hospice part of the building itself contained several distinct spaces.

One such space was that around the offices, reception and tea bar, which was regularly used by some workers and by patients' relatives, and also, although less frequently, by longer-term patients. Administrative and support workers (including the medical secretaries) were more likely to remain in, rather than merely pass through, this part of St Z's. These workers spent their time here, in the offices on the upper level of St Z's, and in the staff dining room next to the kitchen downstairs.

Most of the lower level of the hospice, other than day care, formed another space, which was occupied by domestic and maintenance staff. These workers only

[12] Nevertheless, Bill was (categorised as) a palliative care patient, and Tom (as) an elderly care patient; I will return to this point later in the chapter.

came to the upper level of St Z's to perform specific tasks: the maintenance men to do general repair and maintenance work, kitchen and domestic workers to clean or to bring the trolleys of food at mealtimes.[13]

The two social workers (SW 10 and SW 12) were based mainly in their office (off the corridor beside the hall and chapel) and the physiotherapist (PT 9) in the physiotherapy room on the elderly care ward. However, these three workers moved around the hospice more than other workers. All three spent time on both wards, and in the reception area and tea bar, although they seldom went downstairs, and never used the staff rest room nor the staff dining room downstairs.

Nurses did not usually spend time in the reception area, but occasionally passed through, going to the tea bar to buy rolls or meal tickets which they exchanged for a meal from the kitchen downstairs. Nurses almost always had their breaks and their meals in the staff rest room, where they had a fridge and often brought in their own food. Even if they had a meal from the kitchen they tended to eat this in the rest room, rather than the staff dining room, and I never saw nurses sitting in the tea bar.

The two wards were also spaces which were clearly demarcated from each other and from the rest of the hospice. Most of the nurses arrived on their wards via the rear entrance of St Z's, which they used in preference to the main entrance, since it led more directly to the changing room. They used the changing room on arriving and leaving, and approached the wards via stairs which led to the corridor upstairs which ran between the mortuary, hall and chapel; turning left for St E's and right for St P's. Although the two wards met at a set of double doors at one corner of the building, nurses on day shifts generally stayed on their own ward. For a few months prior to the reorganisation of St Z's, managers assigned day shift nurses from St E's to shifts on St P's, so that they could gain experience of working with palliative care patients, and they were notably uncomfortable with being on a ward other than their usual one (night nurses, however, did move between the wards).

[13] These workers spent most of their time "downstairs," and were rarely seen "upstairs;" thus the "invisible labour" which maintained the hospice generally went on "downstairs," whereas the focus of St Z's, its "business" was "upstairs."

In-patients, other than when they went to services in the chapel[14] or on the occasional day trip, also tended to remain on the wards on which they were staying. Longer term in-patients who were relatively well occasionally used the tea bar, though usually only in the company of their relatives, and sometimes patients from St P's came through to St E's to take part in activities in the activity room. There were also distinct spaces within the wards themselves; the single rooms on each ward were for different "kinds" of patients than those in the four-bedded rooms – differences which, as I will discuss later, were associated with perceptions of how soon the deaths of particular patients were likely to occur.

Day care was an even more distinct space, situated on the lower level of the building, between the domestic parts of St Z's (kitchen and storerooms) and the convent. Most patients were driven to day care, either by volunteers in their cars, or by day care's adapted bus, and approached day care via its own entry at the back of the hospice. If she had not organised a day out, DCC 14 (the day care coordinator) usually spent her days in day care and rarely visited the upper level of the hospice, except occasionally, when visiting day care patients who were staying on the wards.

The doctors (Dr 5, Dr 21 and the three local GPs – two male and one female) came and went via reception, and spent most of their time on the palliative care ward, with occasional visits to the elderly care ward, depending on which patients were on that ward. Doctors rarely went downstairs (other than, very occasionally, to visit a patient at day care), and they did not use the staff rest room nor the staff dining room. Towards the end of my fieldwork, Dr 21 (who came from a hospital-based palliative care team) was employed by St Z's as a second consultant. He wanted to spend time in the staff rest room, but the junior nurses were noticeably uncomfortable about this, and he did not do so during the time I was there. The nurses' discomfort at his proposal to do this echoed their discomfort when he asked them to "call me Pete"

[14] These took place at 11 a.m. every morning, and on most days of the week were Catholic masses, except for Thursdays, when an ecumenical service was held instead, usually given by Rev 19, the minister from the local Church of Scotland.

(that is, rather than "Dr Smith"), their response to which was to call him "Dr Peter."[15] (I return to the issue of job boundaries and hierarchies later in this chapter).

Thus, St Z's seemed to me to be divided into several distinct spaces, which I felt were very different places. However, the physical separation of these spaces was minimal: day care was separated from the rest of the hospice only by a staircase and corridor, and sets of double doors were all that divided the two wards; the convent and the reception area; and the reception area and the two wards.[16] The distinction between these spaces was primarily associated with the fact that different people tended to be restricted (and/or to restrict themselves) to particular areas, and to use these spaces differently.[17] Different spaces contained different groups of workers and different "kinds" of patients.

The separation of people and/in spaces meant that the weekly "case conference" – which most workers called the "doctors' meeting" – was one of the few occasions when workers from across St Z's came together. It was held every Tuesday lunchtime in the meeting hall, which was one of the few places in St Z's used by workers from across St Z's.[18] Since I moved between the spaces of St Z's

---

[15] Again, "Pete," "Peter," and "Dr Smith" are pseudonyms.

[16] It was therefore possible to make a circuit of the upper ground floor of the hospice, passing through the two wards and along the corridor alongside the hall and chapel, but this rarely happened, and when it did happen, this was notable. For example, during the World Cup in June 1998, on a day when Scotland were due to play Norway, I was in St P's when one of the maintenance men and a kitchen worker half-danced into the ward along the corridor from the reception area. He was wearing a kilt and tam o'shanter, while she was wearing a tartan nightie, flushed pink, and looking hugely embarrassed. He picked up the two small Scottish flags which were stuck in half a potato covered in silver foil on top of the monitor at the nursing station, and they danced off to St E's, passing through that ward and ultimately ending up back at reception. This event was not only unusual for the movement around the wards, but also in the non-work related presence of domestic and maintenance workers on the wards, workers who only usually came to the wards for particular work-related reasons. Workers referred to this dance through the wards several times over the following days, and it was part of the general excitement in St Z's over the World Cup: the (England) World Cup song: "Ole Ole Ole" was frequently played in reception, especially when the Matron wasn't around, while the majority of workers, volunteers and patients vigorously supported the Scottish team and opposed the English team, including backing the Argentinian team, both because they beat England, and also because a factory in the west of Scotland made the Argentinian team strip.

[17] Although the distinction between the spaces was accentuated by the colours of the doors and other paintwork within each area: dusty pink in the reception area and other public spaces, dark red in St E's, and pale blue in day care and St P's.

[18] Other than the weekly "doctors' meeting" the meeting hall was used regularly for the children's drop-in and related events, such as the children's Christmas party. It was also used for yoga in the evenings by some workers (support workers rather than clinical or paramedical workers), and also

more than most people, I was particularly well situated to observe the differences across St Z's, and also to observe interactions and connections between people in different parts of St Z's.[19]

I will now move on to a more detailed discussion of day care and St P's and a consideration of St E's, highlighting the differences between these parts of St Z's. I will then proceed to consider the similarities across St Z's, and the paradoxical relationship between these similarities and the differences between its various parts.

DAY CARE

Day care was a particularly separate, almost marginal, space, both physically and also in the perceptions of the people there. Day care was run by DCC 14 (who was an occupational therapist by background) together with an occupational therapy assistant (OT 27) and a nun who was a retired nurse, assisted by 3 or 4 different volunteers on each day. All of these workers had a strong sense that day care was a different place from the rest of St Z's, particularly the wards, as was conveyed in their talk of "downstairs" (which for them meant day care) as opposed to "upstairs" (the rest of St Z's). Day care patients also defined or identified spaces in St Z's in this way.

Patients in St Z's generally tended to remain in the area of the hospice where they arrived, whether that was one of the wards or day care. However, patients who regularly came to day care were occasionally admitted to one of the wards for more intensive care than they could receive at home, or for "respite care."[20] If this happened, or if someone who had arrived for day care as usual was admitted to a ward, both workers and patients commented upon this, and spoke of that person as having gone or being "upstairs."

---

occasionally for job interviews and for meetings which involved the whole hospice staff, such as "Mission Effectiveness" – a series of workshops organised by the mother hospice in London.

[19] As I noted in the previous chapter, this was because when I began my fieldwork the managers asked me to spend time on St E's before going to St P's, and also because for the bulk of my fieldwork, I spent 2 or 3 days each week on one of the wards (for varying lengths of time), and also attended each week's case conference, and spent each Friday at day care and the children's drop-in.

[20] That is, when the person was admitted to the ward for a few days, so enabling them and/or whoever was mainly looking after them at home to have a break.

Sometimes this comment had an ominous undertone, conveying the sense that the person "upstairs" was likely to die. However, although some people were never seen "downstairs" again after they had gone "upstairs," this was not always because they had died. For example, once Des C began being regularly admitted to St P's for periods of respite care, he gradually ceased coming to day care, although his health did not prevent him from doing so. Conversely, a long-standing day care patient, Tommy McL, gradually became too frail to continue living alone at home, and was eventually permanently admitted to St E's, but he continued to come to day care – being brought down from the ward on the days which he had been allocated for coming to day care – until he became too unwell to continue doing so.

Day care workers might occasionally visit day care patients such as Tommy McL, who had been admitted to one of the wards, but it was unusual for them to go "upstairs" otherwise. DCC 14 attended the weekly case conferences (which rarely lasted more than an hour), but other than this she and the other day care workers generally only went upstairs on special occasions, such as celebrating the birthday of a worker "upstairs," or if an "upstairs" worker was leaving the hospice. If they did go "upstairs," day care workers felt uncomfortable, unwelcome and out of place. On one occasion, after they had been invited to St E's for a staff member's leaving celebration, a day care worker commented to me that she was "glad to come back downstairs;" "they didn't even offer us a cup of tea." Day care workers felt similarly uncomfortable at attending "Mission Effectiveness" (footnote 18 above), which was held in the hall "upstairs."

For part of the time during which I was doing my fieldwork at St Z's, while the conversion was taking place, day care was based "upstairs" on St E's. This, however, was an unusual situation – I conducted most of my fieldwork "downstairs," and day care moved back "downstairs" after the conversion had been finished. I will therefore predominantly discuss day care as it was when it was "downstairs," considering aspects of the move "upstairs" towards the end of this section.

Day care was held in a series of rooms. Opening off the entrance hall was a cloakroom and toilet, a rest room for patients, and a small room which was used as a smoking room by the patients. Beyond this room, in a corridor leading to the hospice

kitchen and storerooms, was DCC 14's office. Also opening off the entrance hall was the main site for day care: a large room off which opened a small kitchen. Immediately inside the door into this space was a vinyl-floored area with two round dining tables with four chairs at each, at which patients ate their lunch. At other times these tables were used for playing cards or dominoes, or for activities such as making masks or Christmas decorations. Occasionally, a volunteer would sit at one of these tables to do hand massage or nail-painting with the patients, or workers would sit there alone, for example writing up patients' notes after lunch.

The other part of the main room was a sitting/social area. This was a carpeted space, holding about fifteen easy chairs, arranged along three sides of the space. The right-hand wall was largely made up of windows and a set of French windows, which opened onto day care's garden: a paved space containing a greenhouse, a pergola, and various flowerbeds.

The day care day usually started at 11 a.m., and days spent in day care followed a set pattern. Patients were allocated 2 or 3 regular days a week on which they came to day care (so that a maximum of 12 patients came on any one day), and from 9 a.m. onwards various volunteers drove the adapted bus or their own cars around the surrounding area to pick up those people who were coming to day care and bring them to St Z's. On arrival at day care, workers made patients cups of tea or coffee and brought them cakes or biscuits. If the day was spent in day care, lunch was at 12.30, after which patients would move back into the sitting area, to talk and/or play cards or dominoes. At about 2 o'clock, a member of staff would take patients, volunteers and some staff through a programme of seated exercises, followed by relaxation and visualisation exercises. Tea was at 3, and after tea the patients were taken home, again, either in the adapted bus or in volunteers' private cars, or (very occasionally) by relatives who came to collect them.

Not every day was spent at St Z's, since on two or three days each week (timetabled in such a way that all patients had the opportunity to go out) DCC 14 organised day trips to places such as lochs, castles, villages, seaside towns, the local distillery, shopping centres, and events such as the annual agricultural show in Edinburgh. Day care workers also organised trips to the races, to evening shows or

matinees at Glasgow theatres, and the annual Christmas party. They also occasionally organised weekends away; while I was doing my fieldwork they took patients to Blackpool for a weekend in October (to "see the lights," that is, Blackpool illuminations),[21] and towards the end of my fieldwork they had begun organising another weekend away, this time to Dublin.

Days out

A fairly typical day care day trip was one in mid-June, when we went for a picnic on the shore of a loch, followed by a drink in the nearby pub. While we were sitting having the picnic, workers, particularly DCC 14 (who was sitting with Jimmy D, and sharing her egg sandwiches with him),[22] repeatedly remarked: "Great, this is great." Comments such as: "Isn't this great?" "Are you enjoying yourself?" "How did you enjoy yourself?" were a common feature of day trips; workers repeatedly asked everyone else (workers and patients): "Are you enjoying yourself?" "Are you enjoying your meal?" "Did you enjoy that?"

The sun was going in and out while we were there, and when the sun was in it felt cold. I was only wearing a short-sleeved T-shirt, and Billy MacS took his jacket off, saying: "Here, put this on." I said: "I'm fine, it's not that cold, and the sun won't be in for long." Billy MacS said to the group: "It's just so I can put my arms around her." This kind of remark (termed "banter" or "carry on") was common, and on this occasion it was followed by general discussion about the forthcoming trip to Blackpool in October, and who would be sharing a bedroom with whom. Vol B said to Maggie (a middle-aged patient with learning difficulties): "How about you going in with Jim, Maggie? But we mustn't tell Mary [*Jim's girlfriend*]"; OT 27: "Will Santa Claus come in and give you a kiss again, Maggie? What do you think?"

---

[21] There is a strong tradition in the West of Scotland of visiting Blackpool, often around the time of "Glasgow Fair Fortnight," an annual holiday in July, and again when the Christmas street lighting is erected.

[22] Workers on day trips tended not to eat much themselves, but encouraged patients to eat. Some patients commented that they were "always eating" at day care (see my brief outline of the timetable for days in: cakes/biscuits at 11 a.m., lunch at 12.30, tea at 3). Food in general figured strongly in St Z's, but I do not have enough space in my thesis to address this topic.

After lunch we all went to the pub at the edge of the loch for a drink, paid for out of day care funds, but Billy MacS insisted on buying everyone drinks, saying, "I always like to stand my round." Maggie had two advocaat and lemonades. Vol T: "You need to make sure you take your bottle of advocaat to Blackpool, Maggie." This was followed by more discussion with vaguely (hetero)sexual innuendo about who was going to sleep where in the Blackpool hotel. The trip to Blackpool was a repeated topic of conversation in day care until it took place, and afterwards it was referred to frequently. In mid-October, shortly after the trip to Blackpool, Friday day care went out for a pub lunch and Blackpool was the main topic of conversation.[23]

Day care workers frequently began anticipating particularly unusual events or trips (such as to pantomimes or shows in the city, or the weekend in Blackpool) months before they were due to happen. After the Blackpool trip had happened, it was repeatedly recalled and relived: "Wasn't it great?" Day care workers also frequently remarked (at the time of an event): "Are you enjoying yourself?" and (retrospectively): "Did you enjoy that?" In this way, day care workers reinforced the experience and so the pleasure they hoped patients would gain from trips.

Going back on the bus from days out, OH 27 often organised collective singing of well known songs, such as, "Ye cannae throw your granny off the bus,"[24] and jokes and teasing comments flew back and forth between patients, staff and volunteers. On this particular day, DCC 14 was driving the bus, with Vol A alongside her in the passenger seat:

Vol T: "Look at the wee jockey [*DCC 14*] up the front."

Jim: "They're a real Bonnie and Clyde."

Vol A: "My skin just keeps getting thicker; before you know it, I'll be a size 26."

---

[23] A particular incident which was referred to frequently was the toga dance which OT 27 and two volunteers had performed (wearing coloured wigs and bedsheets) one evening in the Blackpool hotel.

[24] To the tune of "She'll be coming round the mountain when she comes:" "Oh, ye cannae throw your granny off the bus, oh ye cannae throw your granny off the bus, oh ye cannae throw your granny, cos she's your mammy's mammy, oh ye cannae throw your granny off the bus." People were dropped off at their homes still singing; they went along the path to their front doors, singing; people who were still on the bus singing them home. Singing was also a key event at the Christmas party, when many

DCC 14: "You can't have a thin skin, mine's thickening up."[25]

Thus, day trips particularly emphasised the way in which hospice workers saw their role as "cheering up" day care patients. Day care workers perceived day trips and other trips out or away as a key aspect of day care, something which DCC 14 said "did the patients good," especially as "when they're not here they're stuck at home, without much to think about other than their illness." Workers generally aimed to fill patients' time with activities, keep them busy and entertained, and this was often associated with workers actively avoiding talking with patients about death and dying. Instead, "banter" and "carry on" between workers and patients was a regular feature of day trips, where it was more pronounced than on days spent in day care itself, and appeared to be associated with having a good time and "cheering patients up."[26]

Nominally, patients could choose whether or not they went on day trips, but workers actively encouraged them to do so.[27] So, for example, on one occasion a day trip was organised to a local garden centre. When I arrived at day care in the morning, Vol T told me that this was the plan for the day. I went into the main room

workers, volunteers and patients did "their piece," which were often country and western songs, reflecting the popularity of this genre of music in the West of Scotland.

[25] That is, a "thick skin" was necessary to withstand all the "banter" and "carry on."

[26] Some of the male patients routinely "bantered" with the younger female workers and volunteers before engaging in any other, or more serious, talk. There was a tension here, since, while this banter was intended, and generally perceived, as part of the "fun" of day care, a gay patient might well find the heterosexuality of the banter difficult. As far as I know, no patients were gay, but they might well be hesitant about saying so in such an atmosphere. There was also possibly a class issue here; I only once met a middle class patient in day care – a retired doctor with cancer – who came to day care on one occasion, and seemed extremely uncomfortable the whole time, particularly with the "banter," and never subsequently returned. See Julia Lawton's discussion of class issues in a hospice ((2000), *The Dying Process: Patients' Experiences of Palliative Care.* London and New York: Routledge: 34-5; 168-9).

[27] Although workers presented day trips as being mainly for the patients' benefit, they also acknowledged that it was difficult for them if there were patients who did not want to go on day trips. Health and safety regulations did not allow patients to be on their own in day care, and so one or two staff members had to stay behind if a patient or patients did, and, if this happened, the number of workers on the trip was reduced. Further, as day care workers took the bus back to the hospice at the end of a day trip, they dropped patients off at their homes en route. If any patients remained behind in the hospice, then the bus had to return to the hospice at the end of the day to pick up these patients so as to take them home at the usual time. This cut the day trip short, as well as increasing travel time at the end of the day and so being an additional pressure on workers.

and said hello to Des C, who had been staying on St P's for respite care, and who, since his wife had been unable to come to collect him as planned, had been brought down to spend the day in day care. He said: "the wife's not coming to get me today, I could have stayed here [*on the ward*], I was feeling depressed so I would've stayed in bed if I'd known we were going out; I don't know if I really feel like going." As workers began organising things for the trip, I told DCC 14 that Des had said that he felt depressed and that he didn't know whether he wanted to go out. She went to speak with him and persuaded him to come with us, and later commented to me: "of course if they're not feeling well, I wouldn't make them do anything, but sometimes they just need a wee push. Not forcing them, but a bit of persuasion."[28]

Although Des had not wanted to go to the garden centre, he seemed quite content once there, and, while having tea and cakes in the café, he spoke about his feelings with Jim, another patient. A particularly striking exchange was:

Jim: "My girlfriend understands how I feel."

Des: "I disagree with you there; no one knows what you feel like. They might know, they might think they know up here [*taps head*], but they don't know how you're hurting inside. They can't know. Not even your family knows."

Jim: [*mutters of agreement, vigorous head-nodding*] "...But the nurses know."

Des: "Aye, the nurses, those nurses upstairs, they know. I don't know how they do it; I couldn't do it, but they do it."

Jim and Des talked for a little while longer in such terms, and then they themselves changed the subject to what they thought of the tea and cakes. In similar

[28] Another patient, Jimmy C, refused to go to the garden centre on this occasion, however, and he was not to be persuaded otherwise. A factor in this could have been that he was a smoker, and smoking was something which frequently gave rise to tension in both day care and in St Z's more generally, since there were clearly conflicts of interest between workers and patients (patients who smoked did not consider that smoking made any difference to their health, since they were, after all, terminally ill). Smoking was always problematic for day care days out, since the day care bus was non smoking, which meant that smokers had to go without cigarettes for some time (sometimes several hours, depending on the journey), and even after the destination was reached they might not be able to smoke. We were stuck in traffic on the way back from the garden centre, and were therefore late getting back to the hospice, where Jimmy C was waiting to be taken home. As we sat in the traffic jam, DH 14 said to me: "Jimmy's going to be really annoyed and grumbling, but it's a lot, trying to make sure everyone's happy, can't manage it all the time."

situations where workers were present they often interrupted or diverted such conversation, but my presence did not seem to inhibit Des' conversation with Jim, perhaps because I was not trying to change the subject to something else.[29]

Thus, although on days out workers aimed to distract and entertain patients, especially on the journey to and from the place chosen for the trip, once at the venue, workers and patients often split up into small groups of two or three people, and this allowed for intimate talk between patients. This kind of conversation was rare on days spent in day care, however, perhaps because there was less opportunity for one-to-one conversation, owing to the lack of private space.

Days in

Day care prior to the conversion was held in a relatively small space, so people sat very close together, which did not allow for much privacy.[30] This set-up also meant that workers were usually present in close proximity to patients, and, as I will show, workers avoided, and at times actively censored talk about death and dying, aiming instead to distract patients from thinking about their own and others' approaching deaths while in day care. Before and during lunch workers and patients formed a single group, other than those few patients who went to the smoking room to smoke. However, after lunch on days in day care, workers either had their own lunch breaks or wrote up patients' notes, and during this time patients played cards or dominoes and talked amongst themselves. If only a few patients were present, or if most people were involved in doing other things, there might therefore be an hour or so after lunch when patients could talk intimately in small groups before the group exercise at 2 pm, followed by tea before going home.

---

[29] It is possible that if I had not been there they might have been even more open with each other, or, on the other hand, they might have said nothing, but, of course, it is impossible to know either way.

[30] This was even more the case during the temporary period upstairs in an even smaller space. The new day care was more spacious, with an interconnecting series of rooms, the largest of which was big enough to allow everyone to come together for exercise sessions, and also to allow people to break up into smaller groups or pairs, but they only began to use this in May 1999, after I had finished my fieldwork, so I cannot say whether this set-up made any difference.

Jeanie was a patient who I met early on in my fieldwork. Although she had incurable cancer (and was categorised (as, by definition, were all day care patients) as "terminally ill"), Jeanie seemed relatively well,[31] and she was quite open about both her cancer and her strong religious faith. She often spoke about how her faith in God kept her going, although, like most other patients, she did not do so to the whole group, but instead only to me and to one or two other patients, at times when no one else could overhear. After I had known her for a couple of months, I asked her if I could interview her, and she agreed.[32] However, before this could happen, I arrived at day care on a Friday in mid-May and DCC 14 said to me: "Jeanie died; she died at 7 a.m. yesterday; I phoned her yesterday to see how she was, I was concerned after Wednesday [*Jeanie's previous day at day care, when she'd been unwell*]; she'd been up and dressed first thing, she was having her breakfast and then she just went to sleep."

Frank Sinatra had also died the previous day (of cancer, aged 82), and people in day care were talking generally and publicly about this, but not about Jeanie.[33]

---

[31] In recent years, in association with recent medical, including pharmaceutical, developments, incurable cancer has become a chronic illness for some people, that is, a disease with which people can live for a significant length of time, rather than dying relatively quickly after cure is no longer possible. For discussions of this see, for example, Daniel Callahan (1995), *Setting Limits: Medical Goals in an Aging Society.* London: Simon and Schuster; James J Walter and Thomas A Shannon (1990) (eds.), *Quality of Life: The New Medical Dilemma.* New York: Paulist Press. See also Jenny Hockey (2002), 'Dying the way we live,' pp. 51-63 in Rumbold, B (ed.) *Spirituality and Palliative Care: Social and Pastoral Perspectives.* Melbourne, Oxford and New York: Oxford University Press: 55, and Allan Kellehear (1990), *Dying of Cancer: The Final Year of Life.* Chur: Harwood Academic Press.

[32] This was before I had made the decision not to interview patients, which decision (as I detailed in the previous chapter on methodology and analysis) emerged gradually while I was doing my fieldwork. Jeanie's death was a contributory factor in this decision, since if I had managed to arrange the interview with her, I might have done so with other patients, before I began to feel unsure whether spiritual care happened in St Z's. Jeanie's unexpected death was a shock to me, and to others, which is something I discuss towards the end of this chapter. It was also an early highlighting of difficulties with organising interviews, since it illustrated how patients' conditions, even when apparently stable, could change very rapidly, which meant that future plans, however firmly agreed and apparently certain, were liable to change. Des C was another example of a patient with whom I agreed early on to conduct an interview, but with whom it proved difficult to find a suitable time, and by the time it would have been possible to interview him I had made the decision not to interview patients. It's also worth noting that if I had done an interview with Des early in my fieldwork, which was also early in his time in the hospice, when he was very positive and optimistic, it would have been very different from an interview conducted later, when he had become much weaker, and lost his sight, and his associated depression had increased.

[33] A similar thing happened when, later that same year, Linda McCartney also died of cancer.

Although the atmosphere in day care was generally muted, and although workers had told the patients that Jeanie had died, they discussed her death in undertones with other workers, not with the patients.

After lunch, however, while they were playing dominoes, patients (particularly Jim) began talking about the unexpectedness of Jeanie's death: Jim: "Jeanie was being sick on Wednesday." Mary: "She wasn't here on Wednesday." Jim: "Yes, she was." Bill P: "But she seemed alright otherwise."[34]

Thus, while workers told patients if other (current or previous) day care patients were unwell or had died, workers usually discussed such patients with other workers, not with patients. Likewise, patients usually discussed such patients with other patients. That is, any discussions of death or illness were usually held *within* one of these two groups (patients or workers), not *between* them. Workers changed the subject if patients publicly referred to other patients' deaths, and rarely spoke with patients about other patients' deaths or illness. However, workers did talk to day care patients about those day care patients who were on an "upstairs" ward but not perceived as being close to death, and after the deaths of some patients workers often talked about them, in terms of their *lives* in relation to day care, with current day care patients who had known them.

So, although Tommy McL continued to come to day care over a period of time during which he was visibly getting weaker, his changing condition was never commented upon, nor discussed, between patients and workers, but only between workers, or between patients. In mid-May, after he had been on the ward for several weeks, a volunteer brought Tommy to day care in a wheelchair. Tommy was very thin and shaky, and was commenting on his knee and leg pain, but he nevertheless took part in the exercises, intently watching and precisely imitating each move that DCC 14 made, until he fell asleep, before the exercises had finished. Later on that afternoon he started singing a Scottish folk song, in a strikingly beautiful voice (at which Vol C commented in an aside to me: "You think you know someone, but you don't at all").

After day care finished, Tommy McL was taken back upstairs, and this was the last time that he came to day care. Yet workers never discussed with patients how he had been that day (although patients discussed this amongst themselves), nor his gradually increasing ill health subsequently (although workers discussed this amongst themselves). After Tommy died (on St E's) in August nobody in day care mentioned him for a while, but, after a month or so, workers began to speak about him again, reminiscing about how he had been when he regularly attended day care, and about his singing on his last day there (although nobody ever mentioned that that day had been his last day "downstairs").

Day care workers frequently reminisced about patients who had been dead for a while, and these reminiscences often linked to their reminiscences about past events, which might include ex-patients (who were usually ex-patients because they had died). In this way, workers focused on the *lives* of current and past day care patients, and, by avoiding discussing the more recent past and the near future (which, for many patients, entailed/equated with death), workers avoided discussions of death and dying.[35]

That is, day care workers reinforced their own and day care patients' memories of absent day care patients, including patients who had died, but not while these absent patients were close to death or immediately after their deaths. Instead, workers only talked with patients about other patients who were in a stable condition (which could include having been dead for some time). Recently dead or "dying" patients were thus separated from other patients, both in time and in space. That is, day care workers talked with patients about other patients in relation to how they had been when alive, or about other patients who were still living, but never about "dying" patients. So, in their conversations with patients, day care workers emphasised the here-and-now, and past or future events which they expected to be pleasurable, and this focus was reinforced by the regular routine on days spent in day care, and the similarly regular pattern of days out.

[34] Again, as with the day in the garden centre, although I was present, I was not trying to change the subject.

[35] Lawton discusses a similar phenomenon in the hospice which she studied (op. cit., note 26: 46-9).

It was not only day care workers who avoided talking about less well or recently dead people, however; some patients also became uncomfortable when other patients discussed death and dying. For example, Jean W was a patient who first came to day care in late July, and from the outset she talked extremely openly about death. One patient said to me about Jean: "all she ever does is talk about people who've died." On another occasion, Vol B told me that on a recent day trip Jean and Mick had both been in their wheelchairs at the back of the bus and Vol B had overheard Jean listing to Mick all the people she knew who had died. Later some patients complained that Jean spoke so much about death, and DCC 14 asked Jean not to talk about deaths in front of other patients.[36]

Ann G was another patient who was unusual in her openness and frankness in talking about her own cancer, the treatment she had had, and its side effects. She was also quicker to initiate talk about death, and more direct and public in such talk than were most other patients.[37] One day in early June I arrived at day care, got a cup of coffee and sat next to Jimmy C. We talked about the weather, what we had done during the previous week, and the possible plans for that day, and Ann, who was a new day care patient to me, and was sitting across the room from us, joined in. Me: "Even if we don't go out today, it's lovely to sit out in the garden when it's sunny." Ann: "Yes, the gardens are lovely here, and round the front too. A friend of mine was upstairs, he died last year. I used to come up and see him, sit in the garden."

After a while Jimmy C left to have a cigarette in the smoking room, and Ann asked me if I was a volunteer. I replied: "Well, I come here once a week, but that's as part of a study of the hospice I'm doing for a PhD." Ann: "Good for you." After a very brief pause she continued: "I've got liver cancer, it's secondaries, hot spots, but they can't find the primary tumour. I'm having treatment anyway, and I've got a strong faith and lots of friends praying for me. Masses are being said for me; that'll

---

[36] In the event, however, this was unnecessary, since Jean was admitted to the palliative care ward in early August, very soon after she had first come to day care, and died shortly thereafter.

[37] There could have been a religious factor here, since, like Jeanie, Ann G had a strong religious faith. However, I never had an opportunity to discuss this with her, either, since Ann died within a few weeks of first coming to St Z's: she came to day care for a couple of weeks, and was then admitted "upstairs" to St P's, where she died after a few days.

pull me through. God's got my primary tumour, that's what I think. I'm due for more treatment soon; they wouldn't give up on me if they couldn't find the primary, would they?"

This comment by Ann reminded me of a conversation I had had with Des C a few weeks earlier, when he had also seemed to associate treatment with (hope of) survival. He told me that he was feeling "very positive" and would be going away on holiday in a week's time: "I'm doing great, they're all saying I'm doing great, I'm managing to use the zimmer ok now, so I get around. Keep exercising, that's the main thing, keep the muscle strength up."

Dr 5 had recently admitted Des to a local clinic for radiotherapy, and he said that his oncologist had been "very positive, very positive; she says: "We'll win; it won't beat you, we'll beat it." It's a very slow cancer, people can live 10 years with it; they gave me five days radiotherapy; they wouldn't give me all that expensive treatment if there was no hope, would they? I'm to go back in for chemo when we get back from holiday."

Thus, Des, like Ann, was more open than most patients in talking about his illness, and workers commented on this when he was first admitted to St P's, ascribing his openness to his acceptance of his illness and prognosis. I suggest, however, that both Ann and Des's open talk about death was in terms of *not* dying. Neither thought of themselves as dying, because they were receiving treatment, and each perceived the treatments they were receiving as aiming to *prevent* death. That is, they both seemed to be equating treatment with survival/cure, yet this would appear to contradict one of the criteria for admitting patients to the hospice: their awareness of their terminal diagnosis. Thus the questions which Ann and Des asked raise further questions relating to the meaning of "awareness."[38]

It is worth noting at this point that I did not respond to Ann's nor to Des' (perhaps rhetorical? perhaps probing?) questions about hope and/or treatment, partly

[38] For example: what hospice workers perceived as awareness of diagnosis, the basis on which workers classed patients as "aware," and the relationship between "hope" and "awareness." Unfortunately, at the time of my fieldwork I did not pursue these questions, but it would be interesting to explore further how patients and workers understood "hope" and "awareness."

because at this point in my fieldwork I did not feel that it was appropriate for me to engage with their questions.[39] I return to this point and reflect on it further in my discussion chapter (chapter six).

Day care's move "upstairs"

As I noted in the previous chapter, my fieldwork partly coincided with building and conversion work in St Z's. In July 1998, after the new convent had been built and the nuns had moved into it, work began on converting the original convent into an enlarged day care and offices. While this work was going on, day care was temporarily moved upstairs to the "activity room" on St E's (a room which had previously been used for patients to play cards or bingo, or to do craft work).

After this move, day care workers commented that, although they now felt more a part of the hospice, they still felt separate from the ward. DCC 14 said to me that she did not feel that they could spend much time in the activity room, since they "got in the way" of the ward. This sense that they were "in the way" was compounded by the reduced space now available for day care: a single, cramped room for up to 20 people, as opposed to several rooms "downstairs." Day care workers had brought the kettle and fridge upstairs, so were self-sufficient for tea and coffee, but the patients had to use the ward's smoking area and toilets, and the ward's dining room for their midday meal. It was therefore no longer easy to spend all day

---

[39] Nor did I refer Des or Ann to anyone else. This was for various reasons, which I was more or less aware of at the time. One factor was that I was unsure of who I could refer them to, or how to do so without treading on workers' professional toes, since such a referral from me could be interpreted as criticism of their practices. In addition, as I noted in chapter three, I was acutely conscious of my own role boundaries, particularly at the beginning of my fieldwork. I drew these boundaries for myself, seeking to identify myself as a researcher, as distinct from a health care professional. In the early days of my fieldwork, associated with the uncertainty of being in the observing/learning/reflecting phase, prior to testing out my preliminary ideas through participation, my role boundaries were relatively fixed; I restricted my actions, feeling "I'm not qualified." To some extent, therefore, I was echoing and reproducing (having perhaps absorbed) workers' strong sense of role boundaries (which I discuss more later in this chapter). Even when I adopted a more participatory role, however, my sense of "situated ethics" affected the extent to which I felt it was ethical for me to participate in the care of people who were dying (see Bella Vivat (2002), 'Situated ethics and feminist ethnography in a West of Scotland hospice,' pp. 236-52 in Bondi, L et al., *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research.* Lanham, Maryland and Oxford: Rowman and Littlefield, appended as appendix VI).

in St Z's, so DCC 14 organised day trips more frequently, which was tiring for both workers and patients.

Another factor leading to the increased going out could have been that, as a consequence of day care's move "upstairs," day care workers and patients became more aware of deaths in the hospice. The move "upstairs" occurred at a time when several people on the elderly ward died in a period of a few weeks, and was also associated with the reorganisation of St Z's, which, as noted, involved reversing the proportion of patients, from two-thirds elderly to two-thirds palliative care patients. This meant that the beds of elderly patients who died during this time were assigned to palliative care patients, who were both younger and also more likely to die. Thus, the number and frequency of deaths in St Z's increased. So, following the move upstairs, there was less opportunity for talk about death and dying between day care workers or between patients, yet they were more exposed to death.

On a Thursday in November, as the new day care was nearing completion, DCC 14 took workers on a guided tour of the new day care. No patients came to day care on Thursdays, which were set aside for administrative tasks, and following the tour, I returned to the activity room with the day care workers. I asked OT 31 (who had run the activities for the elderly patients when the activity room was used for that purpose, and who had begun helping with day care after it moved "upstairs" to the activity room) what she was going to do after the new day care opened.

She replied: "I don't know, things are all changing so much now, who knows. I can't see that they're going to re-open the activity room… That lady that came in the other day and died, I never knew her.[40] The "no admittance" sign is never off the door [*of the waiting room outside the mortuary*];[41] it used to be when you'd see it, you'd think, "oh, that's a shame, I wonder who's died," now it's, "oh, there's another

[40] Although the first part of this utterance does not necessarily seem to lead to the second part, it seems to me that OT 31 was making a connection along the lines of: the hospice management were not going to re-open the activity room because of the decreasing numbers of elderly patients, numbers of whom were (rapidly) decreasing because of the recent deaths on St E's. This train of thought led OT 31 to reflect on the increased frequency of deaths in recent months.

[41] When the door was closed and the sign was on it, this indicated that there was a dead person in the mortuary.

one," sometimes two or even three in a day. Since July they've all been going. Mary died in July, then Betty."[42]

DCC 14: "Some of them were here for years, five or six years, then they all started to go at once. It's got that it's almost routine going to funerals. I went to one of a friend of mine the other day. It was kind of like, oh, is that it?"

OT 31: "I can see why the girls [*nurses*] in [St P's] stopped going to them [*funerals*], they'd never be on the ward."

Again, this conversation was held in the absence of patients.

So day care's move "upstairs" to St E's activity room highlighted the importance of location and movement for day care workers and patients. They associated certain places in St Z's with proximity to death, and day care's move to St E's was also a movement closer to where dying happened. This meant that people in day care became more aware of deaths, since death and dying was not usually apparent in day care as day care patients were usually relatively well; if they were less well, they did not come to day care and/or went "upstairs."

People in day care also associated particular spaces with talk about death. When they were downstairs day care workers avoided talking about death and dying with patients, and by doing so they silenced patients' talk about death and dying. Thus there was no *collective* talk about death between workers and patients in the shared spaces in day care. However, at times and in places when workers were not present, some patients took the opportunity to talk with each other about their feelings about death, dying and their own losses, including the deaths of people who had attended day care in the past. This happened most frequently on days out, although, when day care was "downstairs," it was possible on days in. When day care was "upstairs," it was harder for patients to have these conversations, yet death and dying was more evident.

[42] Both these women had been on St E's for some years and had regularly participated in activities run by OT 31 in the activity room.

Thus, intimate talk between day care patients occasionally happened, but not when workers were around, keeping things "cheery." When day care was temporarily "upstairs" on St E's, some day care workers extended this "cheering up" approach to patients there.

For example, the "two Tommys" were two long-term residents on St E's. They had fought together in the Second World War and had then taught maths for years in the same school. Having had their families, who had grown up and left home, they had moved into the hospice, and had been sharing one of the four-bedded rooms on St E's (with various other patients at different times) for several years. One of the "two Tommys" (Tommy S) died in April 1998, and the other Tommy (Tommy B) subsequently had a stroke, from which he recovered, although he had lost some of the use of one arm. In July, Tommy B's son, who was also called Tommy, visited Tommy B with strawberries to celebrate his 50th birthday. The following day he too had a stroke, from which he died. Thus, over a very short period of time Tommy B had several losses, and was left very much alone.

After that week's case conference, I went into St E's and met SN 2, who said to me: "We're all gob-smacked just now, Tommy's son died this morning; he was 50 years old." Me: "what happened?" SN 2: "He had a stroke, the same as Tommy had, but he [*Tommy B*] survived it and now his son's gone. He was here the other day, laughing and eating strawberries, we're all gob-smacked. But Tommy doesn't want any fuss, he said 'I'll go and watch the football this afternoon;' he's an old soldier, it's the stiff upper lip." Me: "Is he trying to blot it out?" SN 2: "He can't deal with it." Tommy was sitting in his usual place in his wheelchair in the smoking area, gazing into space.

Despite Tommy B's initial attempt to continue as usual, he subsequently spent several periods of days on end in bed, and when he eventually got up, he sat in a reclining chair rather than upright in his wheelchair. After a few months, he began sitting in his wheelchair again, and one Friday when I arrived for day care (during the period when it was "upstairs" in St E's activity room), he was sitting in St E's smoking area with two male day care patients, looking better than he had for some

time. There was no one else around. I said to Tommy: "How are you, Tommy? You're looking better than when I last saw you, but how are you feeling?"

Tommy: "A long way below ok. They [*St E's workers*] tell me I'm shouting when I try to be heard, and then when I speak normally they don't hear me."

At this point, OT 27 came round from the activity room: "Hello Bella, how are you? How are you, Tommy?"

Tommy: "A long way below ok."

OT 27: "Cheer up; we'll have to find something to make you smile."

OT 27 then said to me that later that morning she was going to a funeral; Mary, a day care patient, had died recently. She also told me that Susan D (a St E's patient) had also died recently, having "slept herself away."

Tommy: "That's a good way to go."

OT 27 did not respond to this, but instead changed the subject to the plans for day care that day. Thus, Tommy's first "a long way below ok" was closed off by OT 27's arrival, while she responded to his second "a long way below ok" with "cheer up." Finally, OT 27 actively changed the subject when he said "that's a good way to go," yet Tommy could have been signalling that he wanted to talk,[43] using subtle cues, perhaps trying to initiate conversation, as with Des C and Ann G (pp. 179-81).[44]

Although OT 27 was a day care worker, her attitude was similar to that of most staff on St E's, who also sought to "cheer the patients up" and keep the atmosphere "light," which, for them, meant not publicly engaging with patients' questions or remarks about death and dying. Workers often perceived distressed or confused patients as difficult, because they did not keep silent about death in situations where workers and other patients did, and were more direct and less oblique in talking about death and dying. For example, Tommy McL, the day care patient I mentioned earlier, who was on St E's for some time, and had some learning

[43] And/or possibly testing whether such talk would be possible at a later stage.

[44] Again, however, as with Ann G and Des C, and for similar reasons, I did not engage with Tommy B's comments either.

difficulties, said to AN 26, following the death of Tommy S: "brr, it's me next." I did not personally hear this latter remark, but I subsequently heard about it frequently, both from AN 26 and from other workers, who all noted how difficult they found it to respond to such a comment.

ST E'S: THE ELDERLY CARE WARD

St E's was L-shaped, running along two sides of the central garden. Offices and single rooms for patients were situated along the outer edge of the corridor which led through the ward, and four four-bedded rooms for patients (two on each arm of the L) were situated on the inner edge of the corridor, with windows which looked onto the garden. Between the two four-bedded rooms on the shorter arm of the L was a small sitting room with a television, with doors which opened out into the garden. Prior to the death of Tommy S, the "two Tommys" often sat in this sitting room watching the television. The nurses' station was at the angle of the L, opposite an open sitting area with a fishtank, next to which was a larger television room. During most of the day most patients sat in the open sitting area or in the television room, often with several nurses and/or volunteers. The television was usually on, although people tended to talk rather than watch it.

In the longer arm of the L were: another two four-bedded rooms and two more single rooms for patients; an overnight room for patients' relatives; the physiotherapist's room; the patients' dining room; and the activity room, where patients played cards, dominoes or bingo, or did craft work, prior to day care's move "upstairs" into this room. Big cupboards in the activity room stored craft materials and paints, games, books and toys for the children's drop-in.

As with days in day care, daily life on St E's followed a very regular pattern. The majority of the people living on St E's, although they were frail and unable to live independently, were not "terminally ill," and were generally relatively well. Workers (6 early shift nurses for 20 patients) got patients up, washed and dressed for breakfast, and in time for those who wished to (five or six people) to attend the 11 o'clock service in the chapel (along with some of the nuns from the convent and

various people from the town). Other patients went to the sitting area by the nursing station or the television room. Lunch was at 12.30 p.m., and those patients who were able to walk and feed themselves had their lunch in the dining room; others were brought their food on wheeled trolleys. The evening meal and drugs round was at 6 p.m., after which the four "back shift" nurses began getting the patients ready for bed.

St E's was generally relatively quiet, although the atmosphere varied depending on who was the nurse in charge,[45] and on days such as St Patrick's Day or at Christmas time, relevant decorations were put up (green garlands for St Patrick's Day) and tapes played – Irish music or carols. As noted, for most of the time while I was doing my fieldwork the majority of patients on St E's were elderly care patients: all the patients in the four-bedded rooms were elderly care patients, while single rooms were allocated to a few palliative care patients. These latter patients were given beds on St E's rather than St P's because they were expected to live longer than the average palliative care patient on St P's (that is, for months rather than weeks). However, they were expected to live for shorter lengths of time than the average elderly care patient (that is, for months, rather than years) and this was why they were kept separate from elderly care patients, if possible. However, as the changeover began to happen this was less possible, and so some palliative care patients were allocated beds in the four-bedded rooms.

Deaths on St E's were infrequent, and the long-term elderly care patients who died had often lived there for years. Workers often found these deaths difficult, because a patient who had stayed on the ward for a long time would have had a long relationship with workers. However, workers also sometimes found deaths of palliative care patients on this ward difficult. One such patient was Tommy McL, who was admitted to St E's in April 1998. Workers there quickly became attached to him. On a Friday evening in mid-August, after the children's drop-in had finished, I passed through St E's, returning toys and books to the activity room, and stopped to talk with AN 26 (an auxiliary nurse on St E's), who was sitting in the men's four-

[45] If SN 32 was in charge, nurses tended to gather in the open sitting area or in the television room, and at these times the ward was noisier and more lively; if SN 7 was in charge, nurses were more often individually with patients in their rooms, and then the ward was quieter.

bedded room holding Tommy McL's hand.[46] Tommy was semi-conscious and close to death, and AN 26 said to me: "it's always the good ones; you never get used to it."

me: "You get attached to them?"

AN 26: "You spend more time with them than with your own family… My friend Joan died 6 years ago in that bed [*pointing across the room*], she had her service in the same chapel as Betty [*a patient who had died recently*]; it all came up for me again [*when AN 26 prepared Betty's body after her death*]. Me and SN 7 came and got her [*Betty*] ready; she had a special nightdress she wanted to wear, had asked us to do it for her, shown us where everything was and everything. I'd been working that day, she died in the evening, they phoned us to come in, we came in and got her ready, left at 11 o'clock, went for a walk in the park."

Thus, one patient's approaching death triggered AN 26's reminiscences of other patients, and of their deaths, and also illustrates how workers developed relationships with patients which were not only professional: AN 26 and SN 7 had not been on duty when Betty died, but, out of friendship, came into St Z's after their shifts had finished to prepare her body, because she "had asked us to do it for her." This conversation also shows that workers' relationships with patients did not necessarily begin in the hospice. AN 26 had had a friendship with Joan prior to Joan's admission to St Z's, which then became a professional-patient relationship as well. This was not unusual, particularly for "untrained" workers, that is, auxiliary nurses and domestic workers. Many of these workers (in contrast to the "trained"/ professional workers such as the medical director, the nuns and the social workers) had grown up and had their families locally; they knew patients prior to their admission to the hospice,[47] or, if they did not know them, knew their relatives and/or

[46] This was the beginning of the changeover, and Tommy McL, although a palliative care patient, was in a four-bedded room.

[47] So, for example, Ann G first came to day care on a Friday in early June, and that afternoon AN 30 (an auxiliary nurse on St P's) came down to day care looking for her (unusually, since it was even more rare for "upstairs" workers to come "downstairs" to day care than for day care workers to go "upstairs"). AN 30 [*to people generally*]: "We're old friends, but we've lost touch over the last few years; [*to Ann*] when I heard you were here I almost died [*sic*]." They sat and talked with each other about their families, and AN 30 explained how she had come to lose touch with Ann. Their

their friends, and their local familiarity meant that they had much in common with patients.

ST P'S: THE PALLIATIVE CARE WARD

St P's was small, with two four-bedded rooms (one for women and one for men) and two single rooms, plus an additional room which was sometimes used if someone was admitted as an emergency, or occasionally as an overnight room for relatives of a patient who was close to death. Thus, there were usually ten patients, very occasionally eleven, on St P's, and the health of these patients varied more widely than that of patients in St E's or day care, where patients were generally, relatively, well.

St P's also had a high staff:patient ratio, with between three and five nurses on the ward at any one time during the day (four or five nurses on the early shift, and three on the "back" (late) shift).[48] The majority of nurses on St P's were "trained," and they were the most constantly present health care professionals on the ward, although the physiotherapist and the two social workers visited periodically, and there was more of a medical presence, with the medical director (Dr 5) present most days (although he did not conduct a ward round as such), and also the local GPs visiting their patients who had been admitted. There were no volunteers on St P's.

St P's was strikingly different from the rest of St Z's, something which I noted and on which both workers and patients commented (without my prompting). This difference in part related to time: as a result of St P's small size and high staff:patient ratio, nurses on this ward had more time and were less "busy" (that is, less engaged on obvious physical tasks)[49] than were nurses on St E's. Associated

---

conversation was unusual, since, while it was held in the public space of the day care sitting room, it was more intimate than was usually the case when many people were around.

[48] In comparison there were similar numbers of nurses on St E's: six on the early shift and four on the late shift, but there were twice as many patients on that ward, and a greater proportion of "untrained" nurses.

[49] See Kath Melia (1987), *Learning and Working: The Occupational Socialisation of Nurses*. London: Tavistock; particularly her discussions of nurses "being busy" and "getting the work done" (pp. 47-8).

with this, St P's had a minimal routine. Fewer patients and more workers allowed nurses to have more time with patients, thus (as both workers and patients pointed out), enabling nurses to give individual patients longer, more personalised care than was possible either in hospitals or elsewhere in St Z's.

The low level of "busyness" made St P's generally more peaceful than other parts of the hospice. At times it could seem deserted, with no nurses at the nursing station, since they were all either in patients' rooms or in the day room between the two four-bedded rooms. There was also a wide variation in the characteristics of the patients at any one time; in particular, in how well or unwell they were (which varied from people who were very close to death to people who were relatively well and there for respite care or for symptom control). Since St P's was so small, differences in patients' characteristics, including (in particular, but not exclusively) their health, had a noticeable effect on its atmosphere, which was occasionally noisy with laughter, but more usually quiet and peaceful. Because of the flexible timing of regular ward activities, the wide variation in patients' health, and the very individualised care associated with this, I am wary about making generalisations about practices on St P's. Instead, I will cite those incidents which I observed there which seemed significant to me, for various reasons which I will highlight.

When I began my fieldwork on St P's I immediately noticed the lack of any marked daily structure, since this contrasted with St E's and day care, where things were very much organised by the clock. On St P's, although some events, such as lunch, drugs rounds, and the handover from one shift of nurses to another, happened regularly, they took place at times which could vary by as much as two hours (although with smaller variations in the timing of drugs rounds). Workers in St Z's often contrasted the two wards on the basis of differences relating to time and routine.

Thus, when I first met SN 2 on St E's (her usual ward), she had just spent a fortnight on St P's.[50] Without being prompted by me, she commented to me on her

[50] This was as part of the process whereby the hospice managers, in preparation for the changeover which would follow the conversion and building work on St Z's, were alternating nurses between the wards, so that nurses spent several periods of two weeks on the ward which was not their usual ward.

experience on St P's, remarking in particular on the flexibility in the mornings, when nurses made piles of toast for breakfast, and made scrambled eggs or porridge as the patients awoke, and as, or if, patients wanted them, which she contrasted with the fixed morning routine on St E's.

Another contrast with St E's was that patients on St P's might spend all day in bed, or take their time in getting up. I was talking with AN 30 (an auxiliary nurse on St P's), on another occasion, and I asked her how long she had been working in St Z's.

AN 30: "6 years ***through in*** St [*E's*], then 6 years here."

me: "Did you ask to come ***through here*** or were you told you were being moved?"

AN 30: "They tell't me; I didn't want to come, I was greetin.'[51] I love it now, there's so much time to spend with the patients; I can take as long as I need to. Not that I'm saying that those lassies ***round there*** don't give good care, but it's like a conveyor belt: I've got two up, one more to get up. Here you give them their bath, do their fingernails, well, you do that ***round there*** too, but ***through here*** if they want a bath, if they want to lie in their bath, they can have one, take their time, do what they want when they want to."

In the above conversation I have emphasised the locational phrases: "through here" (St P's) and "round there" (St E's) which AN 30 (like day care workers with "down here" and "up there") used to contrast "here" – where she was – with "there" – elsewhere in St Z's.[52] AN 30 made this contrast on the basis of time and/for care, and both workers and patients in St Z's often contrasted St Z's with hospitals on a similar basis. Thus, one day in mid-August, Jean W, who was staying on St P's while her breathlessness was being addressed,[53] came to day care. She said to me: "It's good to see you: I missed you. Mind, it's much better ***here*** than in [*the local hospital*], they put you in a corner ***there*** and ignore you; you sleep all the time, that's what it's like. They're not like that ***up there***; they're lovely, they'll sit with you and

[51] Scottish English: crying/weeping.
[52] Note that I also adopted this phraseology.
[53] See my earlier mention of Jean W (p. 179 above).

talk with you." Here Jean W contrasts hospitals – "there" – with St Z's as a whole – "here," and also distinguishes between parts of St Z's, with St P's being "up there," and day care (implicitly) "down here."[54]

Another patient, Mick E, was admitted to St P's in June because he was suffering extreme abdominal pain, which Dr 5 found difficult to address. SN 17 spent hours with Mick, rubbing his back, which gave him some relief from his pain. She and I had previously talked about how she had come to the hospice as a student nurse, when she had found St Z's attractive because it offered the possibility of doing what she called "real nursing," that is, of focusing on the patient's needs, as opposed to her experience on hospital wards, where "the work" came first.[55] The morning after Mick E was admitted to a single room on St P's, I arrived and saw SN 17 rubbing his back. She said to me: "See, you couldn't do this in hospital, could you?" SN 17 spent a large proportion of her shift on that particular day with Mick E, and was able to do so, since there were sufficient nurses to care for the other patients.

Thus, issues relating to time and routine were key in how patients, workers and I identified and characterised the particular atmosphere in St P's, and these issues were used as a basis for distinguishing between "there" and "here," both between St Z's and hospitals, and also between St P's and other parts of St Z's.[56] Nurses on St P's frequently commented that their work on St P's was "what nursing should be," since they were able to spend time with patients without necessarily "doing anything" (that is, without performing obvious tasks related to physical care). The high staff:patient ratio facilitated the minimal routine on St P's and (so), allowed for more one-to-one interactions between nurses and patients. This was particularly noticeable

[54] Again, note the sense of people in day care of the wards being "up there."
[55] SN17 perceived that nurses on hospital wards prioritised the completion of physical care tasks over spending time with patients, which latter activity, in hospitals, was not characterised as "work." This was why she had chosen to come to St Z's once she had qualified. On "the work" of nursing, again, see Melia, op. cit., note 49.
[56] For a discussion of women's relationship with time see Karen Davies (1990), *Women, Time and the Weaving of the Strands of Everyday Life*. Aldershot: Avebury. See also various considerations of time in Ronald Frankenburg (ed.) (1992), *Time, Health and Medicine*. London: Sage.

on Tuesdays, when there were more nurses on St P's, either attending the case conferences, or covering for other nurses who were attending these meetings.[57]

Nevertheless, there were still occasions on which routine/regular activities got in the way of this patient focus, and the nurses did not always feel that they had enough time to spend with patients. SN 16 said to me: "when we get the chance to sit down with them [*patients*], the phone goes, or the doctor comes, or something, and we have to break off." Other "trained" nurses were similarly frustrated with the time which they had to spend on doing drug rounds, ward rounds with some GPs, or writing up patient notes. They perceived these activities as interfering with them "just being with" the patients,[58] while "untrained" (auxiliary) nurses, such as AN 30, who did not give out drugs or write up patient notes, had more time to spend with patients.[59]

In general, however, there was a great deal of intimacy between patients and workers on St P's, which was facilitated by its small size, the time available for workers to spend with patients, and the associated minimal routine. This was compounded by the pre-existing relationships and/or shared backgrounds between workers and patients which I highlighted earlier, and because of which, as I have already commented, workers might have pre-existing attachments to patients and/or might develop these on the ward. This was especially the case for nurses, who spent much of each day with patients, and perhaps particularly so for the auxiliary ("untrained") nurses, who had more time for "just being with" the patients. As I

---

[57] This high staff:patient ratio also meant, however, that if there were more than one or two extremely tired, unwell or comatose patients on St P's, nurses might sometimes find themselves with little to do, particularly towards the end of the late shift, by which time most patients would be in bed and/or asleep.

[58] Nurses' sense of the availability of time for intimacy with patients led to the concern of some nurses that the expansion of the palliative care ward would result in the loss of this time and therefore of the intimacy associated with it. One nurse who was particularly apprehensive about this was SN 23, who was also concerned that the increased focus on technical and examinable competences within nursing generally, and the pressure on nurses (both generally and also within St Z's itself) to become increasingly technically competent and participate in further education would lead to a loss of time for "real nursing" on St Z's.

[59] See Celia Davies (1995), *Gender and the Professional Predicament in Nursing*. Buckingham and Bristol, PA: Open University Press, and her discussion (p. 90) of what S Pembrey ('A framework for care,' *Nursing Times*, 11 December 1985: 47-9) calls 'the Polo mint problem,' where "trained" nurses

noted above, AN 26's friend Joan died on St E's, and AN 26 had also become attached to Betty and to Tommy McL, patients on St E's whom she had not previously known. Similarly, one day I came onto St P's and met AN 30, who said to me: "I went to see Jimmy just now, I said I've just come to say hello, then I'll leave you cos your family's here; he said you *are* family – that means a lot to me; I said to him I'll have to get out of here or I'll greet."[60]

It is not clear from AN 30's remark whether she did not want to cry for her own sake, for Jimmy M's, or because workers were not expected to cry. While managers expected, almost encouraged, nurses to feel and show emotions about their patients, they also warned nurses not to care "too much." SN 3 (a staff nurse in her mid-20s, who had done some of her nursing training on St E's, and, when her training was complete, had come to St Z's, initially to work on St E's, later moving to St P's) commented to me that after patients had died: "it's ok to cry with the patients' families; not bawling or anything, but they know you cared about their relative."[61] Thus, St Z's managers, and workers themselves, expected workers to negotiate a delicate boundary between caring and caring "too much."

Nurses were the most frequent and consistently present professional carers on St P's, but it did not seem to me that they were the only carers. As in day care, patients – particularly female patients – on St P's also cared for and supported each other, both practically and also by sharing their feelings and experiences with one another. This mutual support had both positive and negative consequences: positive in that patients took care of one another (care which was based on shared experiential

supervise and manage others, who deliver the care, and thereby, for the trained nurses, the practice of nursing 'drops through the vacuum in the middle.'

[60] For more discussion of how relationships develop between workers and patients, see Isabel Sumaya-Smith (1995), 'Caregiver/resident relationships: surrogate family bonds and surrogate grieving in a skilled nursing facility,' *Journal of Advanced Nursing*, 21 (3): 447-51, and her discussion of the "surrogate" relationships which built up between residents and workers, particularly "unskilled" workers, in a long term residential home.

[61] Again, see Sumaya-Smith (op. cit., note 60). I sometimes saw workers crying with patients' relatives; on one occasion a young man, George, died on St P's, and when SN 17 met his wife in the corridor, both began to cry. However, this public crying was unusual; workers perceived death and their emotions around death as something which they had to "deal with;" they felt that workers should be caring/attached but not "too much." On "managing emotion" see Arlie Russell Hochschild (1983), *The Managed Heart: Commercialization of Human Feeling.* Berkeley, Los Angeles, London: University of California Press.

knowledge); negative in that, since this support was provided by and for people who were themselves going to die in the near future, it was necessarily temporary, and entailed future loss.

Loss of relationships with others was a particular issue for longer-term patients, who met a greater number of other patients, with whom they had more time to develop relationships. However, strong relationships between patients could also form in relatively short periods of time, in which patients could become strongly attached to each other. Thus, the pain of loss which patients experienced was not necessarily linked to the length of the relationship. The problem of patients losing such intimate supporters is a well-recognised issue for hospices,[62] as is the linked issue of patients witnessing other patients' deaths, sometimes extremely frequently,[63] a point to which I will return later in this chapter.

In the women patients' four-bedded room, they often talked intimately with each other about their feelings, in a way in which I never heard male patients on St P's talking with one another. This is not to say that male patients never spoke with each other in this way, but those of their conversations which I heard tended to be less personal, often revolving around sport. Perhaps in this way male patients' understanding of care for each other involved distracting one another from their personal, painful experience, similarly to how workers in day care and most workers on St E's seemed to interpret care/support for patients as distracting them and specifically **not** talking about their illness or death and dying. This was perhaps related to being in the four-bedded room or in the day room when several other patients were present, more than to gender alone, however, since it contrasted with male day care patients discussing their feelings with each other on days out.[64]

---

[62] See Astrid S Isaksen and Eva Gjengedal (2000), 'The significance of fellow patients for the patient with cancer: what can nurses do?' *Cancer Nursing*, 23 (5): 382-91.

[63] See Hockey's comment on this (Jennifer L Hockey (1990), *Experiences of Death: An Anthropological Account*. Edinburgh: Edinburgh University Press: 172), and also see Thérèse M Mazer (1994), 'Death and dying in a hospice: an ethnographic study,' unpublished PhD thesis, University of Edinburgh.

[64] Judy Harrison, Peter Maguire and Carolyn Pitceathly (1995), 'Confiding in crisis: gender differences in patterns of confiding among cancer patients,' *Social Science and Medicine*, 41 (9): 1255-60, claim that male cancer patients tend to confide only in their significant others (and have a smaller circle of people who they consider to be "significant others"), whereas women tend to have a

Women patients also cared for each other's relatives. Cath was a patient who spent a few weeks on St P's before her death there in August, and had been in the women's four-bedded room with Mary B. A few days after Cath died, I was talking about her with SN 16, who said:

"Jim, Cath's husband, wasn't at all realistic;[65] Dr 5 spent a lot of time with him; he's very good like that; he's always got plenty of time for the patients."[66] Mary B could see that he [*Jim*] still hadn't taken it in, she could see that Cath was very ill; she said to me: he doesn't understand, he needs someone with him to help him..."

Thus, Mary B picked up not only on how Cath was, but also on how Cath's husband, was, to the extent of seeking help for him.[67] Women patients' caring for others was not restricted to emotional care, however. On the August afternoon in day care which I mentioned earlier, Jean W said to me: "Up there [*St P's*] I don't sleep at night; I keep awake watching; watching out for what's going on. If anything happens I'm right on that buzzer. The other night Cath was choking; if I hadn't been there she wouldn't be here [...] I do everything for myself, they only give me a bath or a wash in the morning... There are some [*patients*] up there who do nothing..."

Thus, many female patients felt that they had to look after both themselves and others, even when they themselves were unwell (and, indeed, as with Jean W, even to the point where some female patients judged others for **not** looking after themselves).[68] Some female patients even extended this caring to workers. So, in a

---

wider circle of confidantes. As I have noted, however, I was present when male day care patients confided in each other, and I would also question whether sexual orientation might be a factor in this, since it does not seem to apply to the support groups which gay men with HIV/AIDS in the US and other more developed countries developed in the early days of the AIDS epidemic.

[65] Workers often spoke of patients' relatives as being "realistic," by which they meant that patients' relatives were aware that the patient was going to die.

[66] Again, note the importance which workers attached to having time for patients and for patients' families.

[67] In the next chapter I will discuss how people chose to tell particular workers things such as that Jim needed help – what was special/particular about SN 16. Also see comments on this issue in David Barnard, Anna Towers, Patricia Boston and Yanna Lambrinidou (2000), *Crossing Over: Narratives of Palliative Care.* Oxford and New York: Oxford University Press: 12; 182.

[68] On gendered norms of female caring, see, for example, Peta Bowden (1997), *Caring: Gender-Sensitive Ethics*. London and New York: Routledge.

case conference in May, workers discussed Maggie C, a palliative care patient in her mid-60s, who was staying in a single room on St E's:

Transcript 4.01 Case conference 12 May

Note: in this and subsequent transcripts, I have used italics (in square brackets) where necessary to explain who speakers were and to explain items in their talk. I use underlined italics to indicate where speakers emphasised their talk, and bold italics for those sections of talk which I particularly want to highlight and which I will specifically discuss.

1 **SN 4** [*St E's sister*]: Maggie, Margaret, C, her nausea's making her miserable. Her daughter said that ***she was down in the dumps***.

2 **PT 9**: she's an intelligent lady; ***she knows she's here to die***; she knows that Betty's poorly; she knew Rose [*who had recently died*], and Mary McC[*'s death*] shocked her.[69]

3 **SN 4**: it's counterproductive her sitting there, ***she needs her mind taking off it.***

4 **PT 9**: she loved going to day care.

5 **DCC 14**: she hasn't come since she began feeling unwell.

6 **PT 9**: it's not movement that's making her unwell, even in the old bus she never got ill.

7 **Dr 5**: rather than rushing to medicines, ***we need to get her out and doing things***; not medicalise it. We've taken lots of drugs away and she's fine.

8 **Sr 13**: ***when Betty goes that will be the last of the people she knows.***

9 **Dr 5**: I'll have a chat with her.

10 **Sr 13**: she had an intense conversation with SN 25 on night duty, knows ***time is moving on*** and she's not ready, then later called SN 25 back and said she was sorry and hoped <u>*SN 25*</u> wasn't too upset!

[69] I return later (p. 218) to discuss how unexpected/unanticipated deaths shocked both workers and patients.

I will consider case conference conversations in detail later in this chapter, and I will also return later to discuss workers' use of metaphors of location and movement, such as those I have highlighted in the above conversation: SN 4 (turn 1): "she was down in the dumps," Sr 13 (turn 8): "when Betty goes," and (turn 10): "time is moving on." This conversation also highlights workers' perceptions that long-term palliative care patients' relationships with other patients might cause them difficulties, which I will also return to later (here note comments by PT 9 (turn 2) and Sr 13 (turn 8)). Also note PT 9's comment (turn 2): "she knows she's here to die." Later in this chapter I will discuss how workers predicted patients' deaths, but I want to highlight at this point that PT 9 was not predicting Maggie C's death *per se*, but making a general statement about the indefinite future.

For the present, however, I will focus on Maggie C's apology to SN 25 (reported by Sr 13, turn 10). Workers perceived Maggie C's apology as unusual, and mentioned it frequently, not only at this case conference, but also at a nurses' handover meeting between night and early shifts at which I was present, and on several other occasions that I was aware of. SN 25 herself had told me about it when I had seen her on night duty the previous weekend, three other nurses told me about it independently, and I heard workers discussing it amongst themselves several times.

Thus, this was an exceptional incident, and workers perceived it as such. Nevertheless, female patients often "took care" of workers in similar ways, frequently commenting that they did not want to "trouble" or "bother" the nurses or other workers, since "you're all so good" and the nurses in particular were "angels." As is evident in the case of Maggie C, this "not bothering" nurses often involved not raising questions of death and dying, and coincided with the aim of some workers to distract patients from their imminent deaths, which is also evident in transcript 4.01: SN 4 (turn 3): "she needs her mind taking off it" and Dr 5 (turn 7): "we need to get her out and doing things."

SN 4 was a sister on St E's and her comment reflects the attitude of most workers on that ward, as I highlighted earlier. When I went to St P's I anticipated that workers there would talk about death and dying more openly than workers in day care or St E's, since, as I noted in chapter 3, I began attending the weekly case

conferences before I began spending time on St P's. The main focus of these meetings was on palliative care patients, and during the meetings workers usually discussed patients who had died. I had also heard day care patients talk about the nurses on St P's in a way which suggested that those nurses spoke with them about death and dying.[70]

However, after I had spent some time on St P's, it began to seem to me that although, unlike workers in other parts of St Z's, nurses on St P's did not try to keep patients happy, entertained and distracted, and although they acknowledged patients' approaching deaths to a greater extent than workers in day care or St E's, workers on St P's, also sought to avoid public discussions of death and dying. Further, many workers on St P's felt uncomfortable about death/s. Perhaps surprisingly, some nurses expressed discomfort if dead people were left in the mortuary overnight, and, especially on night shifts, some nurses interpreted events such as doors opening for no apparent reason as being the effect of ghosts.[71]

Although workers on St P's had more time and gave more individually focused attention to patients than workers in day care and on St E's, they frequently did not respond, or avoided responding, to the cues which patients gave (comments such as: "Why me? I've always been a good person"), which to me suggested that patients wanted to raise questions of the meaning of death and dying and of what was happening to them.

Nurses on St P's frequently used people's first names,[72] and affectionate language. So, for example, SN 3 often used the phrase "hi honey," while SN 25 (the night sister) frequently said to patients whom she had got ready for bed: "kiss goodnight," or "God bless." However, the same affectionate phrase, from the same nurse, could invite or block various levels of intimacy from patients. During the day,

---

[70] See for example, the conversation between Des and Jim at the garden centre, p. 174 above.
[71] Some nurses also went to spiritualist meetings, fortune tellers, and other such activities.
[72] Although, as I noted in the previous chapter, this was not unique to these particular workers, but a general feature of St Z's which struck me early on – possibly also a feature of the West of Scotland and/or of working class Scottish people, since the nuns (matron and deputy matron) and doctors did this less, which was perhaps partly owing to class issues and partly because of being higher up the hierarchy.

it seemed to me that nurses tended to use subtle non-verbal communication – such as their intonation, whether or not they made eye contact, whether or not they paused after speaking or asking a question, and, if so, for how long – to block or avoid engagement with patients' "Why me?" questions, and to avoid picking up on patients' even more subtle cues.

Mary D was a patient, who, following her admission to St P's (for her pain, which her GP had found difficult to address), did not sleep for several nights, despite being given increasing amounts of sedatives. She said she was hearing voices, and was afraid to sleep because she had nightmares, and she spent her nights wandering around the ward. Mary was noticeably confused, and at times interpreted all remarks as antagonistic.[73] Nevertheless, at other times she held quite lucid conversations, while she also picked up on remarks that nurses made about other patients' health, subsequently asking the nurses about those patients. On several occasions she approached nurses after they had been with George (a patient who was comatose in a single room) and made comments such as: "Will I be like that, nurse?" These comments disturbed the nurses, and they avoided responding to them, frequently telling each other about them, although portraying Mary as disturbing other patients rather than workers.[74]

The only nurses on St P's who I ever heard talking with patients about death and dying were night nurses, particularly SN 25. I never heard such talk between patients and day time workers, although, as I will illustrate later, case conferences and conversations I had with workers suggested that they *did* talk about these questions with patients.[75] That is, day time workers did not conduct these kinds of conversations with patients in public; indeed, in public they often actively avoided such conversations, both with patients and with patients' relatives.

---

[73] So, for example, on one occasion I was helping SN 17 to make a bed, and Mary D asked me to help her with something. I responded by asking her if she could "please wait a minute," and SN 17 said "Oh, we'll be in trouble now." In the event, however, we were not "in trouble."

[74] Dr 5 eventually resolved Mary's situation by changing her medication (reducing the amount of opiates she was taking).

[75] See, for example, comments by PT 9 (turn 2) in transcript 4.01 above (p. 197), and comments by PT 9 (turn 4), SN 28 (turn 11) and SN 15 (turn 12) about Jimmy M in transcript 4.03 below (p. 211).

So, for example, after Jean W's death, her husband, Danny, came into St P's to return some aids which she had used while still living at home, and to bring a box of chocolates for the nurses. He stayed for a cup of tea and was talking about being unable to work the washing machine, and how he was completing the decorating which he'd begun while Jean was still alive. Someone said: "She was a lovely lady" and Danny responded: "She still is." The nurses' response to this was silence, and then they returned to the earlier jokey conversation about how men can't work washing machines.

Thus, I began to wonder, as I also wondered in day care, whether workers on St P's *generally* avoided engaging with such questions from patients and their relatives, or whether my presence inhibited this. Questions about death and dying interwove with spiritual/existential questions of meaning, so avoidance of the former kinds of questions linked to avoidance of the latter, and therefore had implications for my questions about the spiritual aspects of care. This avoidance, however, was public, and it was possible that workers engaged with such remarks or questions privately, when in one-to-one situations with patients. Such situations occurred more frequently on the wards than in day care, for example, when nurses were getting patients up or putting them to bed. As I discussed in the previous chapter, as I increasingly questioned whether care with a specifically spiritual content happened in St Z's, I increased my efforts to observe it, and began exploring what happened in one-to-one situations in interviews. I also became more selective about those nurses whom I interviewed.[76]

---

[76] I shadowed SN 16 and SN 17 – nurses whose (public) interactions with patients seemed to me to have a particular quality – and SN 25, the night nurse who SN 17 had cited to me (prior to the incident of SN 25's conversation with Maggie C) as an example of someone who gave spiritual care. As I discuss in the next chapter, the perception that there was something particular about these nurses' interactions with patients was not only mine, as was confirmed when, later, some other workers/nurses identified these particular nurses to me as giving spiritual care. I aimed to interview all the nurses I shadowed, and also those workers who were identified by their colleagues as giving spiritual care (as noted, these were often the same people). I sought to explore whether these particular workers engaged with spiritual/existential questions from patients when they were in a one-to-one situation with a patient, and I was absent. However, as I will discuss in more detail in the next chapter, the interviews seemed to confirm that this kind of engagement from nurses was rare, and that many did not give it at all (although it is, of course, also possible that, for a variety of reasons, they did not want to tell me that/if they did.

COMMON FEATURES ACROSS ST Z'S

Thus, workers in all parts of St Z's avoided or even actively silenced public talk with patients about death and dying. However, the ways in which they did so differed from place to place, and the three places in St Z's where patients were present – day care, St E's and St P's – were very distinct from each other.

These distinct places for patient care within St Z's were each associated with a particular set of activities, carried out with patients by a specific group of workers, with varying proportions of "trained" staff, "untrained" staff and volunteers in each space, and with staff in each place occupying particular professional roles. This division of labour between workers (which was particularly evident in case conferences) was a similarity across the whole of St Z's, which, perhaps paradoxically, was grounded in the differences between the parts of St Z's, associated with the perception that patients in each part of St Z's were different, with different sets of needs.

These perceived differences between the different "kinds" of patients in each part of St Z's were (non-explicitly) associated with workers' (and patients') perceptions of how likely patients were to die. So, again, the very differences between the three parts of St Z's produced and reproduced a second common feature across all three parts: the significance which workers and patients attached to patients' physical location and/or movement within or between each part of St Z's. Patients' location and movement was significant precisely *because* of the differences between the parts of St Z's, such that some places were associated with patients who were perceived as more likely to die, and others with patients who were identified as less likely to die. The significance of patients' physical location and movement was especially evident in day care, where the phrase "he's upstairs" carried particular weight, and also in the movement of long-term palliative care patients from St P's to St E's, and the difficulties which workers sometimes experienced when deciding where to situate long-term palliative care patients.

Since patients' locations were so significant, workers across St Z's, but particularly in St P's (where patients were more likely to die), regularly sought to

predict/anticipate patients' deaths. This was especially apparent in case conferences, as was a third feature common to the whole of St Z's: the language which workers (and patients) used when making such predictions. This language featured metaphors of movement, phrases such as: "she's going down" or "he's going downhill," such that people in St Z's expressed their perceptions that a particular patient was more likely to die by talking about them as metaphorically moving elsewhere. That is, people across St Z's metaphorically constructed death as yet another space, which was located elsewhere, usually downwards.

In the remainder of this chapter I will discuss the common features across St Z's which I have outlined above, focusing in turn on patients' physical location and movement; workers' attempts to predict patients' deaths, and the language of metaphorical location and movement with which they did so; and the division of labour between workers.

Patients' physical location and movement

As I have indicated, palliative care patients came to and/or stayed in different parts of St Z's depending on their physical health and (linked to this) managers' predictions of the imminence of their deaths. Palliative care patients whose disease was stable or not progressing fast, came to day care or were given single rooms on St E's, if circumstances prevented them from living at home. Day care patients whose health changed stopped coming to day care and/or went "upstairs." Talk about such patients between patients and workers in day care also ceased – that is, in a sense, this talk also went elsewhere – until they returned to day care, or their health improved, or until some time after they had died.

Other palliative care patients were admitted to the four-bedded rooms on St P's for short periods of respite care or while particular symptoms of theirs were addressed. Most such patients then went home, although a few patients might be given single rooms on St E's. Other people whose symptoms continued to be problematic (particularly people who were in severe pain), or whose disease was

progressing rapidly, were moved from St P's four-bedded rooms to single rooms as/if they became more unwell or comatose.

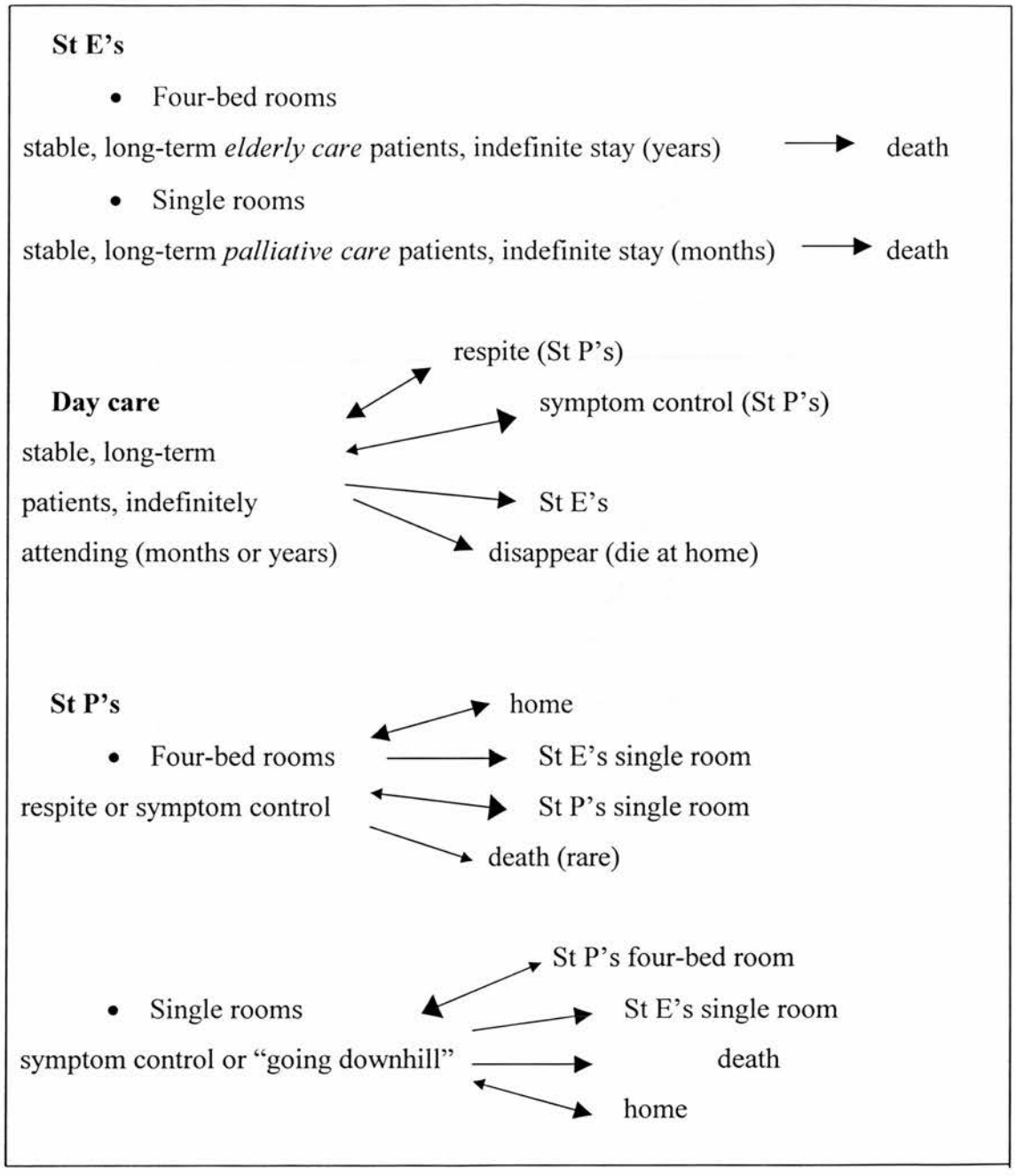
Beds in the four-bedded rooms on St E's were allocated to elderly care patients, who did not have a terminal diagnosis, and were not considered to be likely to die soon. Rather, these patients were living on St E's because, for various reasons, they were too frail to live at home. That is, as with St P's, if a patient on St E's was in a shared room this implied that they were perceived as being less "close" to death. Palliative care patients were occasionally given a bed in a four-bedded room on St E's, if a single room was not available, but workers considered that this was not good for the other (elderly care) patients in the shared room. This became an increasing issue when the changeover between the wards began, since, although St E's was still nominally the elderly care ward, there were too many palliative care patients on the ward for them all to have single rooms.[77]

Thus, the organisation of space and the associated location of patients in St Z's was based on patients' physical health and (linked to this) workers' prognoses for them. This also linked to workers' perceptions of patients' needs, and of which workers could address which needs, such that particular spaces were staffed by particular workers.

I have summarised the location and movement of St Z's patients in diagram 4.1 below, where the arrows indicate patients' movement. A single-ended arrow indicates that patients only moved in that particular direction, while double-ended arrows indicate that patients might move in either direction. The size of the arrow heads in the double-ended arrows indicate how much movement occurred in each direction. Thus, a large arrow head indicates that most patients moved in that direction and a small arrow head indicates that few patients moved in that direction.

[77] For example, Tommy McL (pp. 187-8 above).

Diagram 4.1: Patients' physical location and movement in St Z's



Long-term palliative care patients

So particular spaces within St Z's were allocated to long-term palliative care patients, and it was rare for long-term palliative care patients to be on St P's. Most palliative

care patients either died relatively soon (days or weeks) after being admitted to St P's, or came to St P's for short periods of time, going home again once their symptoms were no longer problematic for them, or after a period (a few days or a week) of respite care.[78] Those few palliative care inpatients such as Bill or Maggie C, who workers thought unlikely to die soon, but who (for various reasons such as lack of mobility or lack of adequate care) could not live at home, were generally allocated single rooms on St E's.

Transcript 4.01 of the case conference discussion of Maggie C illustrated workers' perceptions that intimate relationships between patients raised particular issues for those few palliative care patients who were in St Z's for extended lengths of time. These issues related to the deaths of other palliative care patients and the implications of these, including the losses which they entailed, for patients still living.

Maggie C had been initially admitted to St P's in February because she had particularly problematic symptoms. After a while, her symptoms were resolved, but workers decided that she was not well enough to go home, where (because) she lived alone. However, since Dr 5 thought that Maggie C was unlikely to die in the near future, in mid-March she was transferred from St P's to a single room on St E's. She maintained her friendship with Rose, Betty and Mary McC, women who had shared the four-bedded room with her on St P's, and, when they were well enough, they came and played bingo with her and others in the activity room on St E's. However, all three were closer to death than she was, and they all died while she was still in the hospice, and still relatively well. Thus Maggie C both lost friends and was also reminded of her own imminent death.

Workers in St P's seemed to particularly feel that the different lengths of patients' lives created a difficulty for patients, chiefly in relation to losses. Relatively long-term palliative care patients like Maggie C experienced multiple losses: both of their own capacities and also of relationships with significant/intimate others, both

[78] From the records I kept from case conferences, prior to the changeover of the wards there were usually 2 or 3 long-term palliative care patients on St E's, 2-3 deaths/week, usually of patients on St P's, and 5-6 discharges from St P's. I discuss case conferences in more detail later in this chapter.

other patients – which of course reminded them of their own situation – and also family and friends.

On one occasion, SN 16 commented to me that Jimmy M was: "a deep person, very aware of what's going on; the relationships between people."[79] She went on: "They took him away from home too early; there were all kinds of problems about him getting round at home, I know, but since he's been here his family's here less and less often. At the beginning they were here a lot, but now he's just like someone they visit in the hospice, he's not at the centre of the family any more; he's been home, but sometimes he just sleeps the whole time [*when he's at home*]."

SN 16 here illustrates Jimmy M's slow drawn-out experience of what has been called "social death."[80] That is, in addition to – and amplifying – his experiences of the deaths of other patients, and the associated losses which these meant for him, compounded by the resonances which these deaths had for his own situation, Jimmy M was also losing (his relationships with) his family (relationships which St P's workers were perhaps substituting to some extent, see Jimmy M's comment to AN 30 that: "you *are* family" (p. 194 above)).[81]

Workers elsewhere in St Z's also felt that patients had difficulty with the varying lengths of patients' lives. I discussed earlier (pp. 182-3) OT 31's comments that deaths on St E's had increased in frequency since more palliative care patients had begun being admitted there. At the same time, she also commented: "...mixing up terminally ill and the long-term, it's not fair, it's so hard on them, people dying; you can't mix it; every other day someone dies, it's hard for them."[82] Vol B replied: "The bed gets a bad name," and OT 31 responded: "It's not just that, it's being in the room and the other people dying." Yet, despite workers' sense that this was an issue,

---

[79] By "deep" SN 16 meant that Jimmy M was extremely thoughtful/reflective. I return to the language of "deep" in the next chapter.

[80] See Barney Glaser and Anselm Strauss (1966), *Awareness of Dying*. London: Weidenfeld and Michael Mulkay's discussion in Mulkay (1993), 'Social death in Britain,' pp. 31-49 in Clark, D (ed.), *The Sociology of Death*. Oxford: Blackwell.

[81] Again, see Sumaya-Smith (op. cit., note 60).

[82] Note how OT 31 distinguished between "terminally ill" and "long-term" patients, although, as I've shown, the distinction was not clear-cut: some "terminally ill" people (palliative care patients) were "long-term" relative to other palliative care patients, although "long-term" palliative care patients were

the situation persisted throughout St Z's, being associated with how space was organised. The only way in which workers felt that they could minimise the effects of other patients' deaths on patients still living was by moving people to single rooms on the wards.[83]

Workers implicitly expected that patients on St P's would be there relatively briefly, before going somewhere else; they would not be there long-term. Patients in the four-bedded room on St P's were usually transient, and were fairly rapidly moved elsewhere, either to a single room or back home. Only a very few patients actually died in the four-bedded rooms. So death and dying (like talk about death and dying) seldom happened in shared spaces in St P's (or St Z's more widely), but usually in individual, private spaces, either on the wards or at home.

Jimmy M highlighted the usual pattern that patients only stayed briefly on St P's, precisely because he did not fit it. Workers found deciding where to situate Jimmy M in St Z's problematic. Their difficulty with this also, therefore, highlighted the importance to workers of predicting the likelihood of patients' deaths (since this had consequences for where workers physically located patients), the language which workers used when they attempted to make such predictions, and the complexity of decision-making concerning where to situate patients.[84]

Situating Jimmy M

Like Bill and Maggie C, Jimmy M lived in St Z's for a relatively long time for a palliative care patient, but, unlike them, he was never transferred to St E's. Instead, Jimmy M spent an exceptional length of continuous time on St P's. Jimmy M was in his mid-50s, and was first admitted to St Z's at the beginning of April 1998. He had

expected to live for months, in contrast to palliative care patients who were "going downhill" (and were therefore expected to live for days) or elderly care patients (who were expected to live for years).

[83] Mazer also noted the separation of dying patients in her study of an Edinburgh hospice (Mazer, op. cit., note 63).

[84] Which patients were allocated single rooms involved a complicated decision-making process, concerning who was perceived as being closer to death, and/or whose need for a single room was greater. However, this process was seldom made explicit, and was rarely addressed in case conferences, where it was taken as given that these decisions had already been made by Dr 5 and the senior nurses.

primary lung cancer and brain secondaries, and was unable to use his legs or arms (so he was also unable to feed himself). After a short while, and intensive physiotherapy with PT 9, he regained some movement in his arms, and became able to move about in a wheelchair, but it became clear that his wife could not cope with looking after him at home, in part because the layout of his house would mean that he would be restricted to a single room if he went home. He therefore remained in St Z's, and stayed on St P's for nearly six months, until he died in late September.

Initially, Jimmy M was in a four-bedded room on St P's, and he enjoyed the company of other patients. However, the other patients repeatedly died, leaving him behind. Workers were aware that this was difficult for Jimmy, but they did not feel that they could indefinitely give him a single room on St P's, since single rooms on this ward were used for patients who were close to death. Nor did workers consider it appropriate to give Jimmy M a bed on St E's, since he was a relatively young man, and workers felt that he would find being with elderly people difficult.[85]

Issues relating to Jimmy M's long stay in St Z's were an ongoing focus of discussion amongst workers. So, in the case conference on 5 May, Dr 5 began discussion about him thus:

Transcript 4.02 Case conference 5 May

1 **Dr 5**: Jimmy M; he's well physically and mentally, but ***all the deaths on the ward are bringing him down a bit.*** He's making remarkable progress.

2 **PT 9**: he's talking about progressing onto a zimmer.

3 **Dr 5**: that's code for "get me out of here."

4 **Sr 13**: his wife visits; it takes a great deal out of her.

5 **SN 28**: she said it's their wedding anniversary on the 23rd, but he's not the same person she married.

6 **PT 9**: he's got more freedom here; he can't go out at home; his wife

[85] Thus, workers' predictions of the likely length of Jimmy's life was not the significant factor in where he was located in St Z's. When Jimmy was first on St P's workers did not say that he was "going down," but they began to say this relatively early on in his stay, which meant that they were saying it for a relatively long time. I now wonder whether workers' early move to characterise him as "going down" was a way in which they explained to themselves why he was where he was, but this did not occur to me during my fieldwork, so I did not pursue it then.

couldn't cope long term with him at home.

7 **SN 28**: it's very trying on her.

8 **SN 17**: could we give him a side room?

9 **SN 28**: he tried to talk to Bill P [*another patient*], but he [*Bill P*] didn't answer.

10 **Dr 5**: he's an intelligent guy with lots of insight but physically trapped...

This discussion was never concluded as such, and SN 17's question (turn 8) about a side (that is, single) room was not responded to. Following the final remark from Dr 5, workers paused briefly, and then Dr 5 moved on to begin discussion of the next patient on the list. Jimmy M continued living in the men's four-bedded room on St P's. On a couple of occasions workers moved him into a single room, only to move him back to the four-bedded room when they felt that the need of another patient was greater.[86]

Almost a month later, in the case conference on 2 June, the question of where to situate Jimmy was again raised, and, again, left unresolved. Following that case conference, I was in the tea bar with SW 10, SW 12, PT 9 and HCC 11 (who had just taken up the new post of home care coordinator, having been working as a community palliative care ("Macmillan") nurse for a year, previous to which she had been a sister on St P's). We had all attended the case conference, and PT 9 (referring back to the discussion then) said: "Jimmy's very unhappy." HCC 11 responded: "It's a problem, longstanding patients with other people dying. I remember a lady, we thought we'd done everything we could for her; when she was going home she said to me: "I've seen 17 people die here."[87] Jimmy's not going home, but it's not good keeping on moving him between the ward and a single room. And it wouldn't be good to put him in St E's either; he's a young man still."

[86] Either because a patient was experiencing difficult symptoms or because someone was perceived as likely to die soon.

[87] Mazer (op. cit., note 63) noted a similar, although more dramatically stated, comment when a patient in the Edinburgh hospice which she studied said to her that other patients on the ward were "dropping like flies."

PT 9 responded: "He spent three weeks in [*the local hospital*] for bed rest, with his face to the wall..." As in the case conference, a brief pause followed PT 9's comment and then discussion moved on to a new subject, so, again, illustrating workers' felt inability to resolve the issue of where to situate Jimmy M within St Z's.

A fortnight later, at the case conference on 16 June:

Transcript 4.03 Case conference 16 June

1 **Dr 5**: Jimmy M. 54 year old man with bronchial carcinoma and cranial metastases. ***He's gradually going downhill***, but he's going home this afternoon to watch the [*World Cup football*] match. His wife is upset but realistic. He's very ***down in the dumps***; ***should we try anti-depressants***?

2 **PT 9**: it's a combination of everything, his condition and what he's feeling.

3 **Sr 8**: he's had a lot to cope with, all the deaths on the ward.

4 **PT 9**: he just wants to close his eyes and for it all to go away.

5 **Dr 5**: he's certainly sleeping longer.

6 **PT 9**: is that because he's deteriorating or because ***his mood is low***?

7 **Sr 8**: he feels very tired.

8 **SW 12**: Mary [*his wife*] says he's not communicating much now.

9 **Dr 5**: ***we could give him a wee shot of something to buck him up a bit***. Does he smile at all?

10 **PT 9**: no; it's hard to work with him in fact, because of the lack of response.

11 **SN 28**: he says he's had the best bit.

12 **SN 15**: he said to me ***he knows he's going to die now***, he was improving, but not any more.[88]

13 **PT 9**: he's stopped going to the tea bar...

Note Dr 5's flagging of the possibility of medical intervention for Jimmy M's mood (turns 1 and 9). I consider case conferences in more detail later in this chapter, and will particularly focus on who spoke about what. Here, though, I want to highlight

[88] These comments by SN 28 and SN 15 illustrate how these particular nurses had had intimate conversations about death with Jimmy M.

that, again, this conversation, and the issue of Jimmy witnessing so many deaths, were never concluded nor resolved. As with previous conversations about Jimmy M, following a brief pause, Dr 5 moved on to discuss the next patient on the list. And workers never resolved the issue of where Jimmy M was to be located. As indicated above, this question was first raised by SN 17 in a case conference in early May; finally, towards the end of August, and at his own request, Jimmy was moved into a single room on St P's. A few days after this, SN 16 and I had been talking about how nurses had to balance patients' (sometimes opposed) needs, and she said: "I know Jimmy was finding it hard, all those people dying around him; a lot of people died when he was on the ward."

me: "It's another one of these tensions; patients being around other patients who are dying."

SN 16: "They're a good support for each other, but at the same time it can be hard; they're having the same experience so they can support each other – we can't understand what it's like, no one can unless it's happening to them – but they're also seeing where they're going to be soon."

me: "I know that Jean W found it hard, she felt responsible for Cath, felt that she had to keep watch all the time to see how Cath was; her husband [*Jean's husband, Danny*] told her when Cath died that she had to stop getting so ***involved***."

SN 16: "She went to Cath's funeral and it was after that that she ***went right down***[89] [*pause*] did she tell you that? sometimes they will ***open up*** to an outsider, someone who isn't ***involved***."[90]

---

[89] Note SN 16's retrospective explanation for why Jean "went right down." Several nurses linked Jean's "going down" to Cath's death, that is, as loss of Cath, but, as well as being sadness it could (also) have been loss of purpose (no one left for Jean to look after).

[90] See the point I made in footnote 67 above, concerning how patients would choose a particular person or people to whom they would "open up"/get "close." For a discussion of metaphor, and particularly "closeness," in nursing, see Jan Savage (1995), *Nursing Intimacy: An Ethnographic Approach to Nurse-Patient Interaction.* London: Scutari. Also note the interesting echo of "involved" in these two utterances: I told SN 16 that Jean's husband told her not to get so ***involved*** with other patients; SN 16 responded that patients sometimes "opened up" to an outsider, who is not ***involved*** (that is, with the institution).

Metaphors of location and movement

SN 16's phrase "she went right down" is rather ambiguous, since it could mean that Jean became sad, or/and also that she became closer to death. St Z's workers frequently used "down" in both senses. That is, they often used "down" to mean that someone was unhappy, as in Dr 5's comment in May (transcript 4.02, turn 1) that "all the deaths on the ward were bringing [*Jimmy M*] down," and his later comment in June (transcript 4.03, turn 1) that Jimmy M was "down in the dumps" (which echoes the same phrase which SN 4 used about Maggie C (transcript 4.01, turn 1)). Similarly, see PT 9's comment that "his mood is low" in transcript 4.03 (turn 6). The corresponding metaphor for being happy is "up", and see Dr 5's suggestion (transcript 4.03, turn 9) that Jimmy M might be given "something to buck him up," that is, to reverse his being "down." Also note SN 16's "open up," referring to revealing emotion.[91]

This sense of "down" resonates with another sense of "down," which occurred in the phrases "going down," or "going downhill," such as Dr 5's: "He's gradually going downhill" (transcript 4.03, turn 1). St Z's workers frequently used phrases such as "he's going downhill" or "she's going down" to talk about their sense that particular patients were likely to die in the "near" future.[92] These metaphoric phrases conveyed the sense that the patients being spoken of were moving elsewhere, specifically downwards. To me, these phrases resonate with the significance which people in St Z's attached to patients' actual, physical locations in particular parts of St Z's, and to the movement (or lack of movement) of people (both workers and patients) within and between these different places.

People in day care also used the language of "going down," even though, as noted, since the wards were both "upstairs," being "upstairs" for people in day care carried the implication of someone being closer to death. So, if people in day care

---

[91] See Katherine Froggatt's discussion (Froggatt (1998), 'The place of metaphor and language in exploring nurses' emotional work,' *Journal of Advanced Nursing*, 28 (2): 332-8), of the metaphoric understanding of the body as a container for emotions. Froggatt draws on George Lakoff and Mark Johnson ((1980), *Metaphors We Live By*. Chicago and London: University of Chicago Press), and I will also build on their argument.

[92] This paraphrase "in the near future" is also, of course, a physical metaphor.

said that someone was "upstairs" or "up there," this usually carried the sense that that person was less well. Nevertheless, if people in day care wanted to indicate that they felt that someone was more likely to die, they did not say that that person was "going up," but said, like people elsewhere in St Z's, that the person was "going down/hill." That is, the sense of people in day care that going downwards was associated with approaching death overrode their distinction between "up there" and "down here."

These "going down/hill" metaphors were not entirely euphemistic, since their imprecision reflects the inherent uncertainty in precisely predicting a patient's death. Phrases such as "s/he's dying" would be an inadequate paraphrase, since, as I noted earlier, all the patients who came to St P's were palliative care patients, who could therefore, in some sense, be said to be "dying."[93] When people said that a particular patient was "going down/hill," they were expressing, therefore, their sense that that person had entered a particular phase of "dying."[94] Nevertheless, the use of "going down/hill" metaphors was in part euphemistic, especially when considered in association with workers' avoidance or even active silencing of public talk about death and dying with patients.

I hardly ever heard anybody say that someone was "going to die." In transcript 4.03, SN 15 (turn 12) explicitly used the phrase "he said to me he knows he's going to die now." However, this was an unusual thing for a worker to say, and SN 15 was quoting Jimmy, similarly to PT 9's comment that Maggie C "knows she's here to die" (turn 2, transcript 4.01, p. 197 above). Further, these phrases are more vague as to when the person's death will happen – locating it somewhere in the indefinite future – than "s/he's going down/hill," which conveyed a more precise (albeit still vague) sense of the fairly near future.

---

[93] As already noted (footnote 31, p. 176 above), as cancer has increasingly become a chronic disease with which people can live for years, living with a "terminal" diagnosis has begun to mean something new for a person with cancer. So, while such a person could be considered to be "dying," their position is less distinct from that of all of us than hitherto.

[94] See also Jerry L Morgan's argument that metaphors are neither lazy nor indirect speech, but serve a particular purpose, conveying a precise, specific concept (Jerry L Morgan (1993), 'Observations on the pragmatics of metaphor,' pp. 124-34 in Ortony, A (ed.), *Metaphor and Thought.* Cambridge and New York: Cambridge University Press: 134).

George Lakoff and Mark Johnson hold that we all, unavoidably, use metaphor, particularly when we speak about (more) abstract concepts.[95] They argue that metaphor is creative, reflecting and creating reality, and Lakoff claims that metaphors capture the values, assumptions and hidden meanings that individuals assign to everyday reasoning.[96] Lakoff and Johnson discuss physical metaphors, specifically, what they call "orientational metaphors,"[97] and comment in detail on the metaphoric pair UP-DOWN. They indicate that (for Western/Northern culture) many concepts, such as GOOD, HAPPY, MORE, CONTROL, FUTURE have an upward orientation, which has a positive connotation. Lakoff points out further that, while some cultures do not have the metaphoric pair MORE IS UP and LESS IS DOWN, no culture has the metaphoric pair MORE IS DOWN and LESS IS UP.[98] Lakoff and Johnson argue that what they call "external systematicity" provides coherence between metaphors such that the positive connotations of UP are shared amongst all metaphors with an upward orientation, such as STATUS, VIRTUE, RATIONALITY, HEALTH, LIFE.[99]

Thus, people's shared experience of bodies in space provides a ground for expressing mood and feelings.[100] People's bodies are both repositories and vehicles of meanings, and physical metaphors for concepts are freighted with other

---

[95] Lakoff and Johnson (op. cit., note 92: 112-5) claim that we think metaphorically; that is, that we understand one concept or dimension of experience in terms of another, so that we structure less concrete and vaguer concepts – such as ideas, time, love, and arguments – in terms of more concrete, more clearly delineated, experiential (often physical) concepts. Note my own use of metaphor throughout this thesis; for example, simply in the 2 pages above: "in the near future," people who were "approaching death," "being closer to death," "these phrases resonate." Also note, in relation to Lakoff and Johnson's discussion of visual metaphors for ideas: UNDERSTANDING IS SEEING (op. cit., note 92: 103), my comment that the imprecision of "going down/hill" metaphors "reflects" the inherent uncertainty in predicting someone's death.

[96] George Lakoff (1993), 'The contemporary theory of metaphor,' pp. 202-51 in Ortony, A (ed.), *Metaphor and Thought.* Cambridge and New York: Cambridge University Press. Also see Roger M White (1996), *The Structure of Metaphor: The Way the Language of Metaphor Works.* Cambridge, MA: Blackwell, and Paul Ricoeur (1978), *The Rule of Metaphor: Multi-Disciplinary Studies of the Creation of Meaning in Language.* London: Routledge and Kegan Paul.

[97] Lakoff and Johnson (op. cit., note 92: 14-21).

[98] Lakoff (op. cit., note 97: 240).

[99] Lakoff and Johnson point out that while different subcultures may have different values, and prioritise these differently, the sense of MORE being BETTER and UP is still present, but there are differences between subcultures concerning which thing it is BETTER to have MORE of – whether STATUS, VIRTUE or PEACE, for example (op. cit., note 92: 23-4).

[100] Jenny Hockey and Allison James (1993), *Growing Up and Getting Old: Ageing and Dependency in the Life Course.* London and Newbury Park, CA: Sage: 76.

associations: DOWN (people lie down to die); UP ("fine upstanding fellow").[101] So, for example, compare "things are looking up" with "things are going downhill," or consider the use of "down" in relation to depression and unhappiness. If CONTROL is UP, then "going DOWN" implies the loss of control, being subject to control or an external force. Depression, weakness, vulnerability, and emotions such as unhappiness are all also associated with DOWN, and thus have negative connotations, which interweave and reinforce each other.[102]

Most people in St Z's used these "going down" and "going downhill" metaphors, which conveyed the sense that death involved movement elsewhere, which people in St Z's conceptualised as DOWN, that is, for most people in St Z's death was DOWN. A few people used other phrases, such as "slipping away," or "wanting to go,"[103] which also conveyed the sense of people going somewhere else, but not (necessarily) downwards. So too did a phrase which SW 12 occasionally used, when she spoke of patients being "quite far through." Thus the key feature of the metaphors which people in St Z's used to express that patients were more likely to die, was not necessarily downward movement, as movement *away*, that is, the sense that patients were going elsewhere, somewhere other than "here."[104]

For most workers, however, the elsewhere was "down." In combination with the metaphor that unhappy patients were "down" (relative to "normality"), this suggests that workers conceptualised the usual situation – life or "normality" – as being "here," and death or unhappiness as being somewhere else; usually below "normality," and therefore negative.

Most St Z's workers either had a Catholic background, even if they were not actively practising Catholics, or were Christian by background (again, practising or not). It might seem paradoxical for people in a Christian context to conceptualise

---

[101] See Hockey and James' comment that UP metaphors "high"light positively perceived aspects of life (op. cit., note 101: 15).

[102] Again, see Froggatt (op. cit., note 92), although I question her position that emotions are all negative, since, as outlined above, happiness is UP.

[103] I will illustrate the use of these phrases later when I discuss how workers predicted or anticipated patients' deaths.

dying as moving DOWN, since Christian cosmology is strongly vertical, such that for Christians heaven is UP.[105] However, for Christians (and other religions or belief systems with similar vertical cosmologies), going UP to heaven is something which happens *after* death;[106] dying happens *before* death. So, in relation to these particular metaphors which people in St Z's used, a person goes DOWN as s/he dies, and UP after death.[107]

Workers' use of "down/downhill" phrases was particularly noticeable in relation to Jimmy M, since they were anticipating his death for a long time.[108] They were able to keep using these phrases for such a long time because the phrases were vague as to time (that is, as noted, these phrases were not solely euphemistic), but it was still noticeable that workers' use of these phrases about Jimmy M decreased midway through his stay, as they became increasingly uncertain about how long he would live.

---

[104] See also Hockey (op. cit., note 63) and her discussion of how people in the residential home in the North East of England which she studied also talked of people "going downhill fast" or being "on their way out" – that is, also moving elsewhere.

[105] See as an example the powerful visual image of the escalator to heaven in the film 'A Matter of Life and Death,' directed by Michael Powell and Emeric Pressburger (UK, 1946). Heaven being UP is not only the case for Christians; UP is also venerated by the Shinto religion in Japan, in contrast to, for example, Buddhism, which has no such vertical cosmology – see Yoko Yamada, Yoshinobu Kato, Tetuji Ito and Yuichi Toda (2002), 'The spatial representations of this world and the next world in Japanese, Vietnamese, British and French drawings,' paper presented at 6th International Conference on Death, Dying and Disposal, York, September 2002.

[106] Christie Davies argues in 'Modernity and the "demoralised" afterlife' (paper presented at 6th International Conference on Death, Dying and Disposal, York, September 2002), that in modernity the afterlife no longer entails a moral reckoning, since people no longer perceive going to hell as an option after they die, it is either heaven or nothing/nowhere.

[107] "Going down" and "going downhill" might seem similar to "going up" and "going uphill," and so equally possible as metaphors by which people might express this concept. However, I suggest that because Christians (and people within a Christian culture) particularly associate UP with heaven, using "going up" or "going uphill" as a metaphor for someone approaching death might carry the implication that they were already dead (on their way UP to heaven). For Christianity, dead people go from "here" (below) to "there" (above); they go somewhere else (upwards) and do not come back, in contrast to belief systems such as Buddhism or Hinduism, which conceptualise the movement as circular: life-death-life.

[108] Perhaps workers' early move to characterise Jimmy M as "going down/hill" were in part a way in which they explained to themselves why he was where he was.

Workers' anticipation and prediction of patients' deaths

I indicated above that Maggie C was shocked by Mary McC's death, but it was not only long-term patients like Maggie C or Jimmy M who found patients' deaths difficult. As I discussed earlier (p. 176), Jeanie's death was unexpected, and, *because* of this, it shocked me, and also shocked everyone else in day care (both workers and patients). This was a very early experience for me of the shock associated with being unprepared for patients' unexpected deaths. I found it hard to hold to the knowledge that people who came to day care had "terminal cancer," particularly if they had few or no obvious disease-related symptoms. Some day care patients were frail, but this was not incongruous since most were elderly, as were most patients in St Z's.

I was of course aware that patients were "terminally ill," but this was an abstract, intellectual awareness. Immediately after Jeanie's death my awareness that patients' health could change abruptly was significantly heightened, but this was difficult to maintain, and gradually waned if I did not consciously, actively, and repeatedly, remind myself that patients were likely to change condition and/or die at any time. If I did not do so, it was a shock to me when someone like this died.[109]

Although Jeanie died early in my fieldwork, I do not think that my shock at her death was related to this timing, since I already had experience of people dying. Further, I was similarly shocked towards the end of my fieldwork at the death of a patient to whom I was also close (and who was in a single room on St P's, with all the significance which that carried). The key thing which produced the shock was the unexpectedness of these deaths. Shock at someone's death may seem strange in a hospice context, where it might be thought that people expect other people to die. However, workers, regardless of the length of their experience, were also shocked in such circumstances,[110] and it was noticeable that workers in all parts of the hospice

[109] My active and conscious reminding of myself that people could die at any time also relates to "seizing the moment," which issue arose in relation to conducting interviews (see previous (methodology) chapter), and was also especially relevant to spiritual issues (see next (spiritual aspects) chapter).

[110] See also the discussion of shock, on the part of both workers and researcher, at the unexpected death of a hospice patient, in Barnard et al. (op. cit., note 67): 300-1.

was also evident that workers began predicting deaths even when a patient was not particularly close to death.

For example, Betty, a long-standing day care patient, was admitted to St P's in April 1998. In the case conference on 5 May, Dr 5 said: "Betty's ***slipping away slowly***." On 15 May (the Friday when Jeanie died), while day care workers were discussing Jeanie's death, OT B said: "Betty's lying up there [*on St P's*] ***wanting to go***, but it's not her time." The following week, DCC 14 told me, just before the case conference on 19 May began: "Betty died on Saturday, it was a relief, she was miserable, ***wanting to go***." So, for a fortnight, workers were anticipating and predicting Betty's death, and the consequence of this was that every time they (and I) came to St Z's during that fortnight, they (we) were prepared for Betty to have died.

Workers' anticipation of patients' deaths, and associated self-preparation, happened frequently in relation to patients who were admitted to St P's indefinitely (that is, not admitted for explicitly short-term stays such as respite care). Thus, from the beginning of the admission of such a patient to St P's, workers were, on some, more or less explicit, level, assessing how imminent their death was likely to be. Such predictions were important for where patients were to be located in St Z's, because, as I have shown, where patients were located/moved from or to was associated with the perception of how likely they were to die. Predictions of how imminent death was likely to be were also important for workers' personal preparation, being prepared for the patient to start moving away from "here" to "there" (that is, death). Perhaps such predictions were also important in workers' decisions concerning how close a relationship to form with patients.[111]

---

[111] This was certainly true for me in some situations, such as Jimmy M's lengthy stay in St Z's, and the very slow change in his health, which reminded me of my mother's life and death. I therefore specifically chose not to get close to Jimmy M (hence my focus in this chapter on workers' relationships (and perceptions of their relationships) with him, rather than on his perceptions). (Again, this raises issues relating to the wider question of how/why particular relationships formed between particular people). Also, as I discussed earlier, following my shock at Jeanie's unexpected death I began to actively and consciously remind myself that people could die at any moment. This was distinct from anticipating/predicting when that moment would be, but was closer to the general statements which workers made, such as "he knows he's going to die" "she knows she's here to die," which, as noted, did not have the same, more immediate, sense as "s/he's going downhill." Also see the focus in day care on the vague or distant, rather than the immediate, future.

Betty did in fact die relatively soon after workers first predicted her death, although the time of her death was not precisely predicted – although OT B said on the Friday that it wasn't Betty's "time" (that is, that she wasn't likely to die), Betty in fact died on the next day (Saturday). At other times workers' predictions were even less accurate, and often well in advance of when the person actually died. With a patient like Jimmy M, who lived for a relatively long time in a fairly stable state, the tension of being prepared daily for his death lasted for months. As I have noted, Jimmy M was first admitted to St Z's at the beginning of April 1998. At the case conference on 5 May which I discussed earlier (transcript 4.02, p. 209), Dr 5 said that Jimmy M was "well physically and mentally" and was "making remarkable progress." However, the following week, at the case conference on 12 May:

Transcript 4.04 Case conference 12 May

1 **Dr R**: Jimmy M, a 54 year-old man with lung cancer and cerebral metastases. ***He was having sleep problems, his Temazepan was increased.***

2 **SN 6:** he's sleeping better now.

3 **Dr 5:** ***he had problems with his catheter***; he pulled it out.

4 **SN 23:** it's alright now. He's gone out for the day; has been looking forward to it.

5 **Dr R:** ***how about his muscle power?***

6 **PT 9:** it's the same.

7 **Dr 5:** ***has anyone spoken to his wife? How are the days out?***

8 **Sr 13:** his wife says she's getting better at telling him that she can't manage things.

9 **PT 9:** she feels better about him going home; I told her about the equipment that was available, but that he would be housebound.

10 **SN 6:** he says going home isn't an option for him.

11 **Sr 13:** Mary [*his wife*] says she will do whatever Jimmy wants.

12 **SN 6:** ***she thinks he's going down as well.***

which, as noted, did not have the same, more immediate, sense as "s/he's going downhill." Also see the focus in day care on the vague or distant, rather than the immediate, future.

13 **PT 9:** I've noticed that his speech seems to be slower, he's more thoughtful, not interested in conversation so much, thinking things through.

Over a month later, at the case conference on 16 June from which I also quoted above (transcript 4.03, p. 211), and which I reproduce here for convenience:

Transcript 4.03 Case conference 16 June *(reproduced from p. 211 above)*

1 **Dr 5**: Jimmy M. 54 year old man with bronchial carcinoma and cranial metastases. ***He's gradually going downhill***, but he's going home this afternoon to watch the [*World Cup football*] match. His wife is upset but realistic. He's very down in the dumps; ***should we try anti-depressants***?

2 **PT 9:** it's a combination of everything, his condition and what he's feeling.

3 **Sr 8:** he's had a lot to cope with, all the deaths on the ward.

4 **PT 9:** he just wants to close his eyes and for it all to go away.

5 **Dr 5:** he's certainly sleeping longer.

6 **PT 9:** ***is that because he's deteriorating*** or because his mood is low?

7 **Sr 8:** he feels very tired.

8 **SW 12:** Mary [*his wife*] says he's not communicating much now.

9 **Dr 5:** ***we could give him a wee shot of something to buck him up a bit.*** Does he smile at all?

10 **PT 9:** no; it's hard to work with him in fact, because of the lack of response.

11 **SN 28:** ***he says he's had the best bit.***

12 **SN 15:** ***he said to me he knows he's going to die now***; he was improving, but not any more.

13 **PT 9:** he's stopped going to the tea bar...

Yet, 3 weeks after this, at the case conference on 7 July (that is, almost 2 months after workers had first anticipated/predicted Jimmy M's death):

Transcript 4.05 Case conference 7 July

1 **Dr R**: Jimmy M, admitted on the 3rd of April with lung carcinoma. He's sleepy and drowsy; today's the first time he's been awake at lunchtime for ages. ***It's a very slow deterioration.***

> 2 **SN 6:** he says he's square-eyed with watching the football: "we woz robbed; Batty, what do you expect with a name like that?"[112]

Thus from May 1998 workers were predicting Jimmy's death, and this continued (although, as I have noted, its frequency decreased for a couple of months in the middle of his stay) until he finally died in September 1998.

Thus, Jimmy M did not actually die until four months after workers first said that he was "going down." As I have indicated, it seemed to me that a key factor in workers' (early) self-preparation for Jimmy's death was that they generally liked him, and anticipated feeling grief after he died, so they began to prepare themselves for his death well in advance. Workers' self-preparation did not only relate to anticipated grief, however. Cathy G, another patient who workers unquestioningly expected to die imminently following her admission to St P's,[113] in fact recovered and finally returned home. Workers' predictions of Cathy G's imminent death seemed to me to be associated more with their impatience with what they perceived as her unreasonable demands and expectations than with any sadness which they anticipated feeling after her death.[114]

The inaccuracy of workers' predictions concerning Cathy G's death was not unusual, and thus the shock and surprise of people dying unexpectedly was often mirrored with the surprise when people did *not* die, despite the expectation that they would.[115]

A more general point which I also want to highlight from the above transcripts is the particular content of comments by specific professionals. So, for example, doctors' focus on physical health and physical actions (medical

---

[112] Note the humour which Jimmy M displayed in this comment, even at a time when workers thought that he was "deteriorating." (Batty was the surname of an English footballer who missed a crucial penalty in a World Cup match, so putting England out of the World Cup).

[113] Indeed, I sat with Cathy G shortly after this admission, while she was apparently (and according to workers) in a pre-death coma.

[114] Cathy G highlighted the difficulties which workers had with patients who did not respond to care as they (workers) wanted, and so illustrated the interweaving of care and control in St Z's, which was a significant issue, but beyond the scope of this thesis.

[115] Workers' predictions might appear to themselves and each other to be more accurate than they were, since, if people said often enough that someone was "going downhill," then, when that person

interventions), such as, in transcript 4.03, Dr 5, turns 1 (asking about trying anti-depressants) and 9 ("give him a wee shot of something"); in transcript 4.04, Dr R (GP), turns 1 (sleep problems) and 5 (muscle power), and Dr 5, turn 3 (catheter problems). Although note that Dr 5 (transcript 4.04, turn 7) also expressed concern about Jimmy's wife. In contrast, the nurses and PT 9 in these transcripts pay attention to other issues. This division of talk was a noticeable feature of case conferences, and I will now move on to explore this feature of these discussions.

CASE CONFERENCES

Nurses from the two wards met on their breaks, and workers from all parts of St Z's met in passing in the corridors; on fundraising activities, such as sponsored walks; and at the Friday evening drop-in for bereaved children.[116] But most staff met most regularly at the weekly case conference, which was held at lunchtimes on Tuesdays, and attended by nurses from both wards, the two social workers, the physiotherapist, the day care coordinator, the medical secretaries and the doctors (the medical director/palliative care consultant and one or two of the three local GPs who were associated with St Z's). I began attending these meetings at the outset of my fieldwork, while I was spending time on St E's and in day care.[117]

Case conferences began at 12.30 p.m. and usually lasted about 40 minutes. They followed a regular pattern, structured following a sheet prepared by Dr 5's secretary. This listed (in the following order): day care patients; "present patients" (that is, palliative care patients, who were grouped in two sections: those on St P's (usually between seven and ten people) and those on St E's (usually two or three people)). Next were listed in-patients who had died (usually two or three people);

---

actually died, the chances were high that someone would have fairly recently predicted their death, and so that prediction would appear to have been borne out.

[116] The workers who were regularly involved with the drop-in were the two social workers and the day care coordinator (these three women also spent a lot of their time together at other times), plus various volunteers, and, very occasionally, one or two nurses.

[117] Thus my perceptions of them changed after I had begun spending time on St P's, and began to know the patients who were being discussed.

and, finally, those patients who were being discharged or transferred elsewhere (usually five or six people).

A doctor – usually Dr 5, but, if he was away, then a GP – always led the meeting, and always began by discussing palliative care patients on St P's, to whom most attention was paid, and on whom, therefore, most time was spent. Next came palliative care patients on St E's, who were usually discussed more briefly, while day care patients were seldom mentioned. Next, variable lengths of time were spent discussing patients who were going to be transferred or discharged. Patients who were leaving St Z's were only mentioned if future plans were complicated for some reason.

So, case conference discussions concentrated mainly on palliative care patients, and focused upon people who were in situations which were complicated by physical or social factors. Palliative care patients on St P's tended to be in the most complex situations, followed by palliative care patients on St E's, who were longer term, and tended to be in more stable situations. Elderly care and day care patients tended to be stable (if they were not, they became palliative care patients), and these patients were less frequently discussed, if at all.

The final group of patients who were discussed were those who had died, but these patients were not always mentioned. GPs did not usually comment on patients' deaths, whereas Dr 5 usually did, although to a varying extent, and, again, mostly when deaths were perceived to have been complicated in some way. However, deaths which had "gone well" were also occasionally mentioned. For example, when Ann G died in mid-June, at the case conference the following week, Dr 5 said:

Transcript 4.06 Case conference 23 June

1 **Dr 5**: we should mention Ann G; she died last week. She was very breathless when she came in, but, with morphine in her syringe driver, she settled down well.

2 **Sr 8:** she was well supported by a big family, they coped really well, rallied round and did all the right things, being quietly there.

As here, the nuns (Sr 8, the matron, and Sr 13, the deputy matron) usually tended to comment (or be the first to comment) on deaths in response to Dr 5.[118]

The following week, however, five patients died on the palliative care ward. This was an unusually high number of deaths, so it was an exceptional situation, but I will focus on it as an illustration of how workers discussed patients' deaths at case conferences. Dr 5 was leading the case conference that week and, after those patients who were on the wards and those who were leaving the hospice had been talked about, he said:

Transcript 4.07 Case conference 30 June

1 **Dr 5**: we should say something about all these deaths... ***Billy was a good one***.

2 **PT 9:** I didn't recognise him, the weight had dropped off him.

3 **Sr 8:** ***he had a quiet and peaceful time*** before his death, ***helped his nephew and others***.

4 **SN 23:** ***he calmed down*** in the last few days.

5 **Dr 5:** ***he was drugged up***...

6 **Dr 5:** John Logan: youngish man in the side room, multiple myeloma. He had a bit of quality time in the last few days; we managed the symptom control. How's his wife?

7 **SW 12:** no specific care from the social services...

8 **Dr 5:** ***Martha Brown, she had a good interval***.

9 **Sr 8:** great character, loveable person...

10 **Dr 5:** Michael Kelly, didn't last long, had a haematemesis in hospital...

11 **Dr 5:** ***Peggy didn't do too badly in the end***.

12 **Sr 8:** how was Tom [*Peggy's husband*]?

16 **SN 17:** he cried a lot, the family was concerned, felt he wasn't coping.

17 **SW 12:** he put on the same façade he'd used all the way through, deals with it in his own way.

18 **Dr 5:** it stressed him out that she took so long to die.

[118] I was never sure whether they responded (in their roles/identities) as nuns or as senior nurses.

19 **SW 12:** there've been various family stresses over the years...

20 **Dr 5:** quite a few deaths.

21 **HCC 11** [*to St P's nurses*]: busy week.

22 **SN 28/SN 17:** hard.

It is worth noting that workers evaluated some patients' deaths as "good" or as "not too bad," for example Dr 5 (turn 1): " Billy was a good one," and (turn 11): "Peggy didn't do too badly." The implication of this language was that the person had died as workers thought appropriate or beneficial for them and/or their family, and also suggests that workers perceived other patients as *not* doing well, or even that they "did badly." That is, workers perhaps evaluated some patients' deaths as "bad," although I never actually heard the statement that anyone's death had been "bad."[119] It would be interesting to explore in more depth what workers meant by these evaluations (some of which is suggested in Sr 8's comments in transcript 4.06, turn 2, and in 4.07, turn 3), but this is beyond the scope of my thesis, and I did not explore it in any detail during my fieldwork.[120]

In relation to this, it is also worth noting that workers used first names for some patients and full names for others, for example "Billy" (turn 1) or "Martha Brown" (turn 8). As I noted in my discussion of my use of pseudonyms this was

---

[119] Workers *did*, however, express their perceptions that some patients were "difficult" people, although they seldom did so explicitly. More often they implied it by their tone of voice or the content of their remarks ("it's Des C *again*;" "she's never happy;" "you can never please him") or by gestures, such as casting their eyes upwards. I never heard workers speak of these particular patients as having "done well," and so, perhaps, by implication, workers were comparing these patients to other, "good," patients. See Roger Jeffrey's argument that what he calls "moral evaluations" are conducted in many medical settings, which he illustrates by discussing casualty workers' evaluations of patients as "the usual rubbish" or "good patients," describing "good" patients almost entirely in terms of their medical characteristics (Roger Jeffrey (1979), 'Normal rubbish: deviant patients in casualty departments,' *Sociology of Health and Illness*, 1 (1): 90-108) (although see Robert Dingwall and Topsy Murray's critique and extension of Jeffrey's analysis (1983), 'Categorization in accident departments: 'good' patients, 'bad' patients and 'children',' *Sociology of Health and Illness*, 5 (2): 127-48). See also Martin Johnson and Christine Webb (1995), 'Rediscovering unpopular patients: the concept of social judgement,' *Journal of Advanced Nursing*, 21: 466-75, and their discussion of the physical and/or emotional labour which patients must perform in order to negotiate a "good" reputation.

[120] As with Cathy G, however, note how this illustrates the interweaving of care and control, since, while the aim of a "good death" has a benevolent intention behind it, the imposition of a particular model can be controlling (for a discussion of care and control see Hockey, op. cit., note 63).

sometimes in order to distinguish between two patients with the same first name,[121] but not always. Further, some patients were called affectionately by their first name and others affectionately by both their first and last name, such as Martha Brown. However, workers always referred to patients to whom they did *not* feel close by both their first and last names, such as "Des Clark," who workers never called "Des."

My main aim here, however, is to focus on which workers spoke about which issues, and to highlight that in case conferences different workers focused upon different issues (of which the instances above are broadly typical). The particular focus of each worker linked to and reflected their awareness of their professional roles, and limits to and boundaries between these roles.[122]

Case conferences were strongly (stereotypically) "medically" oriented, that is, they focused mainly on "medical" issues: patients' physical health: their illnesses, diagnoses and treatments. Doctors led the discussions, presenting patients as "cases," with phrases such as: "This 54-year old man with prostate cancer was admitted on the 12th of June..." (this way of opening discussions about patients was particularly the case with the GPs). Dr 5 spoke about medical interventions, such as in transcript 4.07: "he was drugged up" (turn 5); "we managed the symptom control" (turn 7). However, in contrast to GPs, although Dr 5 always spoke about medical interventions, he did not do so exclusively, but also occasionally attended to social and emotional issues. The end of talk about each patient was marked with a pause, and the doctor who was leading the case conference chose when to break this by beginning to speak about the next patient.

Other workers rarely spoke during case conferences, except to respond to specific questions and/or to make specific points. When they did speak, their comments related to their area of perceived expertise (in both their own perception and that of other workers). Thus, staff nurses commented on patients' emotions and patients' families; the social workers focused on issues such as patients' families and

[121] For example, Jimmy D and Jimmy C in day care; Tommy B and Tommy S (the "two Tommys") and Tommy McL on St E's; or when someone's first name was common, such as "John Logan," turn 6, transcript 4.07.

[122] The private, personal, and professional roles of the two nuns who were nurses (matron and deputy matron) overlapped – see footnote 118 above.

social services, particularly if the patient's home situation was perceived as complicating a patient going home; doctors commented on physical issues; and the nuns/chief nurses on their perceptions of patients' emotional health, and of the manner of their deaths. Workers such as PT 9 or DCC 14 whose training included being aware of emotional or social issues for patients or their families, also commented on these issues in relation to patients whom they knew.

Wider discussions between workers more often occurred after case conferences, often flowing from issues raised in the meetings. So, for example, after one case conference in March, I went to the tea bar to write up my notes, and PT 9 and SW 12 were there, deep in conversation with one another. They did not break off when I sat down near them. When they got up to leave, SW 12 said to me:

SW 12: "I hope you don't think we were anti-social..."[123]

[***me***: *"Oh no, that's fine, I was writing up my notes anyway." PT 9 smiles, nods, leaves*]

SW 12: "...we were discussing things about patients - we don't always get the chance to talk about things; things you want to know about the patient. It's harder than you'd think to share information with someone, we're all so busy rushing about, it's difficult to find time to talk to each other."

me: "And there isn't much time in the case conference?"

SW 12: "Or things occur to you at the end, or they're not appropriate to raise in the round."

So, case conferences were largely medically focused, and most workers perceived them as being for the doctors' benefit (hence most workers used the term "doctors' meetings" for what the doctors called "case conferences"). Workers followed doctors' lead in these meetings, seldom addressing "non-medical" issues, except in response to the lead of doctors or the matron. This meant that much "non-medical" communication between workers took place outwith the case conferences, as

[123] Note how SW 12 was "looking after" me/my feelings; as discussed earlier, this kind of looking after was common in St Z's.

indicated above. This was where the social workers, the physiotherapist and the day care coordinator tended to discuss patients with one another and to focus on similar issues, particularly family concerns. Nurses on the wards shared information with each other during the handover to other shifts, and occasionally spoke with the social workers, the physiotherapist and the day care coordinator if they had specific pieces of information to pass on to them and/or if a particular issue or question arose for a particular patient.

Linking to this, workers were extremely conscious of their areas of expertise, and of limits to these, and were acutely mindful of role boundaries.[124] I was particularly aware that DCC 14 felt that there were distinct limits to her role, associated with her perceptions of the limits to her knowledge and competence. This linked to her perception of the function of case conferences. After a case conference in early May (soon after Tommy McL had been admitted to St E's), DCC 14 asked me: "How did you find Tommy?" She continued: "It wasn't the same person they were talking about... we can pick up on how they are emotionally, but not when it's side effects of drugs, that's not my job to know that ... when we're in the new day care we'll have nursing workers, have regular meetings with that input, have more to contribute at the weekly meeting ... we need regular medical care downstairs, at the moment it's the goodness of their hearts."

The two social workers were, similarly, highly conscious of the boundaries and limits to their roles, as were nurses. For example, both "trained" and "untrained" nurses spoke of what was appropriate for each "kind" of nurse to do, such as handling drugs being something which was a "trained" nurse's responsibility. Similarly, on one occasion during a weekend shift, SN 29 was apprehensive about giving a drug to a patient on St P's, and telephoned Dr 5 at home for reassurance.

Doctors and the nuns/chief nurses did not express such hesitancy about what they felt was appropriate for them, or the limits to their expertise. However, most workers in St Z's were perceived by other workers, and also by themselves as responsible for a particular area/aspect of a patient/patients' needs, and this was

highlighted in (who said what in) case conferences. Thus, case conferences produced and reproduced the division of labour between workers, and illustrated how "total care" at St Z's was divided amongst the members of the "multi-disciplinary team," and between parts of St Z's.[125]

Further, despite the general culture of open, smiling friendliness (which was genuine, yet at the same time implicitly obligatory/expected by managers),[126] together with the frequently asked question: "how are you?" and the general use of people's first names (which suggested an egalitarianism which was not entirely superficial), case conferences seemed to me to be the situation in which the unspoken, semi-implicit hierarchy headed by the doctors, the matron and the deputy matron was most evident. That is, the professional (knowledge) hierarchies which were constantly present in St Z's were particularly evident in case conferences. These hierarchies were also apparent in uniforms;[127] in workers' use of spaces in St Z's and their practices in those different spaces; and also in the few exceptions where people were not addressed by their first names alone: the doctors, priests and nuns.[128]

---

[124] Also see nurses' discomfort at "Dr Peter" wanting to spend time in the staff rest room, to which I referred above (p.166).

[125] As noted, this reflected the location of particular "kinds" of patients, perceived as having different needs, in different parts of St Z's, with (therefore) different "kinds" of workers in those different places

[126] See Hochschild's discussion (op. cit., note 61) of airlines recruiting cabin workers with open and friendly personalities and (then) using these characteristics as a resource; these characteristics, she argues, are then expected from them, becoming part of their professional role (or part of Goffman's "front stage" self, see Erving Goffman (1971), *The Presentation of Self in Everyday Life*. Harmondsworth: Penguin).

[127] Nurses, the physiotherapist and the domestic workers wore uniforms, each of a particular colour associated with their professional role; the nuns, including those who were nurses, wore habits; while the doctors, social workers and day care coordinator did not wear uniforms.

[128] That is, as I noted in the methodology chapter, doctors were addressed as Dr + Surname (except for "Dr Peter"), priests as Father + Christian_name, nuns as Sister + Christian_name. These observations echo Jennifer Hockey's claims (op. cit., note 63: 191-4) that an implicit hierarchical system existed in the hospice which she studied, despite the use of first names for all workers, and managers' perceptions of the organisation as egalitarian. Hockey asserts that this implicit hierarchy was evident in the colours of workers' uniforms and in how space was organised in the hospice, and she argues that hospices have been assimilated so easily into British society because they appropriate "traditional forms [...] of power [...]: professional, social and gender-based hierarchies."

CONCLUSION

I have argued that St Z's seemed to me to be a collection of different places, with both workers and patients restricting themselves or being restricted to certain areas, and that this was associated with a variation in practices, both between the different parts of St Z's and also between different workers (both professionals and volunteers) *within* those different areas. So, despite the sense of people in day care, when day care was "downstairs," of the distinction between "up there" and "down here," day care was not so much a particular physical space, as the people who went to day care, and the activities in which they engaged. This was evident in that day care workers still considered day care to be distinctly "day care" even when it was temporarily located "upstairs" on the elderly care ward (St E's). Although this temporary location minimised the physical separation between day care and St E's, it did not affect day care workers' perceptions of these areas as separate and self-contained. If anything, being "upstairs" heightened these perceptions and the sense of day care workers that they were a separate part of the hospice.

Thus, space in St Z's was highly structured, associated with different "kinds" of patients, and, in turn, with different kinds of workers. Space in St Z's was structured in relation to patients' dying, and so in relation to patients' physical health. Patients were implicitly of different "kinds," relating to their perceived proximity to death. This was the basis on which patients were situated in particular places in St Z's, and workers moved patients to different parts of the hospice as they perceived patients' proximity to death to change.[129] Thus, patients' physical characteristics were prioritised, and the different "kinds" of patients were perceived as having different needs, which different workers addressed. This division of labour between workers meant that care was also fragmented; particular workers were located in particular spaces according to their specific responsibilities for specific aspects of care.

[129] Similarly, see Hockey's discussion of how workers in the residential home which she studied moved residents to particular parts of the home depending on whether they were defined as "fit" or "frail," and how this movement produced and reproduced the categories of "fit" or "frail" for both workers and residents (op. cit., note 63: 117).

Thus, both workers and patients, across the whole of St Z's, had a strong sense of the importance of patients' location in St Z's, and where and if they moved. Linked to this, workers often sought to predict patients' deaths, and they used metaphorical language when doing so, most frequently saying that someone was "going down" or "going downhill." People in St Z's occasionally used other metaphors, but all their metaphors conveyed the sense of movement away/elsewhere. Thus, St Z's workers stayed "here" (in whichever part of the hospice they were based), while patients moved (away), both physically (literally) (for example, leaving day care for a ward, leaving a four-bedded room for a single room) and metaphorically (going "down" (towards death)).[130]

People in day care did not think of day care patients as moving "down," but as stable. Day care patients whose physical health changed moved somewhere else: "upstairs," and/or usually stopped coming to day care, before dying some while later. Thus, people in day care did not associate death and dying with day care, but conceptualised them as occurring somewhere else. Within St Z's, people in day care associated death and dying with "upstairs" (the wards), and so day care's move "upstairs" to St E's was also a move closer to death and dying. The increased frequency of days out once day care was upstairs was perhaps associated with workers' discomfort at this, not only with being in a smaller space and feeling "in the way."

Workers on St E's, however, generally considered that patients there were stable, particularly patients in four-bedded rooms. While some elderly care patients did die on St E's, this was rare prior to the changeover between the wards, and St E's patients usually lived in St Z's for years. Deaths on St E's were usually of palliative care patients, who were usually in single rooms.

[130] I will also briefly note here that when St Z's workers spoke about spiritual issues and/or about addressing or engaging with patients' (or their own) questions of meaning, they also used metaphors of movement, which usually emphasised depth: "getting deeper." I also noted above (p. 207) SN 16's comment that Jimmy M was a "deep" person. Deep and down are conceptually related, as are the sense of movement conveyed by "going down" and by "getting deeper." I will return to this in the next chapter, when I also return to the issue of metaphors.

So too, most patients who died on St P's were in single rooms, and, if possible, workers moved patients who were perceived as being close to death into these rooms. The intention of doing this was to minimise distress to these patients, and to other patients, and to enable their friends and family to spend intimate time with them. However, it also meant that workers effectively concealed patients' deaths from other patients, and from other people in St Z's, and so care and control were interwoven.

Thus, death and dying in St Z's were individualised and privatised,[131] occurring in particular metaphorical and physical spaces, which were located elsewhere than shared, public spaces. It has often been argued that hospices participate in the sequestering of death and dying from mainstream social life,[132] and Lawton counters this, claiming that only a particular type of dying is sequestered in hospices – the "disintegrating" patient with an "unbounded body."[133] However, contrary to Lawton, it seemed to me that not only did St Z's sequester death and dying from the wider community, but, even within St Z's itself, death and dying were sequestered, such that they occurred (or people expected them to occur) in particular spaces, and not in others.

Time, like space, was also structured in St Z's. Days on both day care and St E's were highly structured, although the activities in each place were different. In both these parts of St Z's workers focused on keeping patients occupied (although this comprised more active "carry on" in day care than on St E's, where patients, although not "terminally ill," tended to be older and more frail).

Day care was a very structured environment, staffed by occupational therapists and volunteers, in which much collective activity, involving all the workers and patients, took place. Most interactions between people in day care therefore occurred in large groups, and the focus was very strongly on the here-and-now, with occasional reminiscing about the relatively distant past or anticipation of future days

[131] See Philip A Mellor (1993), 'Death in high modernity: the contemporary presence and absence of death,' pp. 11-30 in Clark, D (ed.), *The Sociology of Death.* Oxford: Blackwell.
[132] For example, again see Mellor, and also Hockey (op. cit., note 63: 156).
[133] Lawton (op. cit., note 26).

out. As noted, day care workers perceived day care patients as stable; not "going down." Talk in day care was also stable; usually day-to-day trivia and "banter." Day care workers actively set out to distract patients from talk about death and dying, both patients' own deaths and also those of other people known to them. Workers perceived their distractive behaviour as a caring activity, but it also had a controlling aspect, since their behaviour effectively silenced patients' discussions of death and dying. In this way, as with the movement of patients between and within wards, care was interwoven with control, since caring for some patients implied and entailed controlling (silencing) others.

This was not necessarily a problem, since it is possible that some patients did not want to talk about intimate issues in such a situation and/or with workers.[134] Nevertheless, other patients did want to have such conversations, perhaps especially people who had no close friends or relatives with whom they felt they could talk about such issues. Thus, there was a tension between patients who wished to talk about death and dying and those who did not. Workers usual response to this tension was silence, which coincided with the apparent inclination of most workers not to talk about these issues. Thus, conversations between day care patients about death and dying most often occurred on days out, when gaps might occur in the structure, so enabling people to separate into groups within which, and according to which, people (including workers) felt comfortable with talking, or not talking, about these issues.

St E's was also a highly structured environment, although patients' activities were not as thoroughly organised as in day care. There were 20 or so patients in St E's, and this ward was staffed by five or six nurses during the day, about half "trained" and half "untrained," and a few volunteers. GPs occasionally visited patients on St E's, and very occasionally Dr 5 would visit palliative care patients who were staying on St E's. PT 9 was based in a room on St E's but most of her activities were with palliative care patients, while the social workers rarely visited this ward.

[134] Also see debates over the "medicalisation of everything," and discussions of whether professional intervention is inappropriate for some issues, for example, Ivan Illich (1995), *The Limits to Medicine: Medical Nemesis: The Expropriation of Health*. London: Boyars.

Most patients spent most of each day sitting in the day room with other patients, various "untrained" nurses and a few volunteers. On most mornings activities such as craft work or dominoes took place in the activities room, and there was a daily service mid-morning in the chapel, which a few elderly care patients attended.

The structures and organisation of day care and St E's, linking with attitudes on the part of workers, meant that patients in these two parts of St Z's had little opportunity to discuss death and dying. I never heard workers in day care or St E's discussing patients' deaths, ill-health and/or dying with other patients in public, shared spaces. Such discussions usually only took place between workers or between patients, and although I heard day care patients having such conversations, I never heard patients in St E's doing so. There were relatively few nurses on St E's, and so the opportunity for one-to-one interactions between workers and patients seldom arose.

While space was also structured on St P's, time was less so than elsewhere in St Z's. Activities on St P's were far less organised than in other parts of St Z's, and, unlike workers elsewhere, workers on this ward did not focus on keeping patients occupied and distracted. No group activities took place in St Ps, but those few patients who got out of bed during the day would sit together with other patients in the day room on St P's, or occasionally go to day care or the activities room in St E's. Most patients on St P's were at a different stage in their illness from patients on St E's or in day care; they were closer to death and/or their ill-health or dying were more evident.

St P's had the highest worker:patient ratio of all parts of the hospice, and was the least "busy" part of St Z's. The atmosphere on St P's was noticeably different to elsewhere in St Z's, and nurses were gentle, loving and unrushed. There were usually about 10 patients on St P's, and it was staffed by four or five nurses during the day, most of whom were "trained." The social workers, physiotherapist and Dr 5 were most evident on this ward, and GPs occasionally visited.

There were therefore more occasions on which workers on St P's could discuss death, dying and related issues with patients and their relatives. Yet workers did not always take these opportunities. I occasionally heard St P's workers engaging

publicly in talk about feelings and emotions, but usually only briefly, while explicit public talk about death and dying between workers and patients was rare.

It seemed to me that, while workers on St P's acknowledged patients' approaching deaths to a greater extent than workers elsewhere in St Z's, they nevertheless tended to conceal death and dying from shared, public spaces, both physically (moving patients who were "going downhill" into single rooms) and by avoiding talk about death and dying in shared, public spaces. As elsewhere in St Z's, workers in St P's were generally uncomfortable with public talk about death and dying, and also seemed to identify death as something which had to be prepared for and anticipated.[135]

Thus, although there were distinct spaces in St Z's, associated with workers' perceptions of patients' proximity to death, there were similarities between and across these distinct spaces. These similarities were perhaps particularly evident to me, not only because my role was partly observational (associated with my role as ethnographer), but also because I moved between the spaces more than most people.

One similarity across all of the spaces in St Z's was, as I have highlighted, workers' tendency to avoid public conversations about death and dying (and related issues) with patients and their relatives. It seemed to me that patients seldom overtly raised issues relating to death and dying with workers, but instead gave subtle indications that they wanted to engage in such discussions (for example, Tommy B saying that he was: "a long way below ok"[136]), and I suggest that in this way patients were testing how receptive workers were likely to be to such conversations. (I explore this further in the next chapter).

The perception that these three parts of St Z's were distinct was not only mine but also that of workers and patients, and this perception of difference was (perhaps paradoxically) another similarity across St Z's, associated with workers' relatively self-contained, independent working within their particular part of the hospice, where

[135] Both for patients' benefit and for their own, since managers expected workers to control their own emotions (caring), and workers identified feelings around death, their own and others', as something to be "managed" or controlled, which control was identified with care.
[136] Note here the sense of sadness being downwards: "below ok."

they concentrated on their own roles as members of their immediate team. Workers in the different parts of St Z's did not often interact other than at case conferences, and in these meetings people focused on their particular areas of responsibility, which linked to their domains of perceived expertise/competence.

Thus, another feature which was common across the whole of St Z's was workers' strong sense of their role boundaries and of the expertise and responsibilities associated with their particular roles, something which was particularly evident in case conferences. "Multidisciplinarity" in St Z's meant the division of labour between the members of the "multi-disciplinary team." St Z's workers perceived that individual patients' needs were met not by individual workers, but by the whole of the multi-disciplinary team, members of which had distinct roles and responsibilities. That is, workers in St Z's considered that all the activities of the multidisciplinary team resulted in care for all the needs of patients and their families. (Again, I will explore this further in the next chapter).

This division of labour was associated with an effective hierarchy between the members of the multidisciplinary team. In turn, this was linked to an effective hierarchy of patients' pain, needs, health and care, whereby (as with allopathic medicine generally) the physical aspects of these were prioritised. These were the main focus of the medical director and the GPs, were addressed first in case conferences, were the focus of initial care, and determined where patients were situated/located in St Z's. Social/emotional/psychological issues followed (addressed primarily by nurses and the workers in the "professions allied to medicine" ("PAMs"), that is, the two social workers, PT 9, and DCC 14 – in her professional orientation as an occupational therapist). Explicitly spiritual issues were never discussed in case conferences.

I have scarcely mentioned priests and ministers in this chapter, and this reflects my observations in St Z's, where, although religious professionals, such as Rev 19 and Catholic priests (particularly Fr 18) conducted services and were available for any patient who wanted to see them, they were only apparent on the wards when visiting a specific patient who had asked for them.

As noted, I felt that the time available, and the associated minimal routine, on St P's facilitated a definite intimacy between workers and patients there, and that their interactions had a different quality than elsewhere in the hospice. Most nurses on St P's valued the time they had for performing physical care tasks in a tender loving way, and for talking with patients about themselves and their families. Initially, I thought of this "TLC" (tender loving care) on St P's (that is, gentle, affectionate talk and unrushed, attentive care, which Dr 5 spoke of as "good old-fashioned nursing," and many nurses on St P's talked of as "how nursing should be") as relating in some way to the spiritual aspects of care. That is, I associated the spiritual dimension of care with a particular *attitude* on the part of the carers.

However, as I became increasingly aware of the prioritisation of physical issues, and the frequent, active avoidance of public talk about death and dying, and as I reflected more on this, I gradually began to question what, if the spiritual aspects of care were (only) a tender, loving attitude, then distinguished these aspects of care from the emotional or psychological aspects of care. I began wondering what particular *content* of care would be specifically spiritual, asking myself whether the "TLC" I observed on St P's had a spiritual content, and intensifying my efforts to identify the specifically spiritual dimensions of care in the hospice. And I gradually began to think that the content of this care might perhaps relate to engagement with the "big" questions of the meaning of life and death, or "Why me?" questions.

As noted, my observations of public interactions between workers and patients indicated that workers tended to avoid conversations about issues relating to death and dying. I wondered whether such talk only occurred in one-to-one situations, where, by definition, I was not present, and so I could only explore what happened in such interactions indirectly, through interviews.[137] One-to-one interactions between workers and patients did not often happen in day care or St E's, but occurred more frequently in St P's, since the nurses on St P's had more

[137] Mazer (op. cit., note 63) attempted to overcome this problem by concealing herself behind curtains and French windows so as to eavesdrop on one-to-one conversations between nurses and patients in the hospice which she studied. When I originally read this, prior to beginning my fieldwork, I considered it unethical, but my perception changed as I too found it difficult to observe these interactions.

individual time for patients. Alongside my participant observation I conducted interviews with workers, exploring their perceptions of the spiritual aspects of care. In these interviews I hoped to gain some understanding of what happened in one-to-one interactions between workers and patients, and in the next chapter I will move to discuss material from these interviews.

- 5 -

SPIRITUAL ASPECTS OF CARE IN ST Z'S

INTRODUCTION

In this chapter I will discuss issues relating to the spiritual aspects of care in St Z's, focusing on those few workers in St Z's who said that there were distinct spiritual aspects of care. I will move from considering the difficulties that most workers had with talking about these aspects of care to explore the metaphors of location and movement which workers often used when they talked about spirituality – metaphors which were similar to those which, as I noted in the previous chapter, they used to speak about people who were approaching death. Finally, I will discuss those (even fewer) workers who considered that they personally provided spiritual care.

As I briefly discussed in the previous chapter, in the early stages of my fieldwork in St Z's, I became aware of a particular kind of interaction between patients and some workers which I thought of as possibly spiritual. As my fieldwork progressed, however, I began to distinguish between the attitude of workers towards patients – which I thought could be considered spiritual in *manner* – and care with a spiritual *content*. I therefore began searching for a specifically spiritual content to care, and this search evolved, alongside my participant observation and interviews, as my fieldwork progressed. In this way, this search paralleled and interwove with my increasing questions concerning the characteristics of the spiritual aspects (if any) of care in St Z's.

I noted in the previous chapter that people (both workers and patients) in St Z's were generally aware of, and sensitive towards, religion and people's religious allegiance, probably because of the particular situation of this Catholic-run hospice in a Protestant town in the West of Scotland. Most workers distinguished between religious and spiritual care, perhaps because of this sensitivity towards religion, and perhaps also because this distinction is generally expressed within the hospice movement.[1] Nevertheless, few workers in St Z's identified any specifically spiritual

[1] See for example Shirley du Boulay (1984), *Cicely Saunders: The Founder of the Modern Hospice Movement*. London: Hodder and Stoughton.

aspects of the care which they gave to patients. Most workers elided spiritual care with emotional care and/or equated it with the manner of care – "tender loving care" ("TLC"). Of those few workers who claimed that spiritual aspects of care existed or were possible, most found defining the characteristics of such care difficult.

When workers in St Z's spoke about spirituality and spiritual care they used metaphors which were related to depth and distance, using words such as: "beneath," "beyond," and "deeper." Similarly to the "going down/hill" metaphors which I discussed in the previous chapter, these metaphors were not unique to St Z's workers. However, and again linking to my discussion in the previous chapter, I will build on George Lakoff and Mark Johnson's discussion of metaphor[2] and suggest that the use of these metaphors by workers in St Z's was significant because of what these particular metaphors implied about workers' concepts of spirituality and spiritual care.

The metaphors which workers used when they spoke about spirituality and spiritual care located spiritual issues (metaphorically) elsewhere. For some workers, this sense of elsewhere implied that movement (again, metaphorically) was necessary for workers to "get to" patients' spirituality. This metaphoric movement occurred both in the *character* of the relationships between workers and patients – getting "closer" – and also (linked to this) in the behaviour of workers, from "doing" things for patients to "being there" with them. These workers thought of this "being there" as consisting of an active presence, rather than being a passive act, and "being there" had various facets: signalling availability to discuss existential or spiritual issues; being alert for cues from patients which suggested that they wanted to discuss such issues (cues which were often subtle); and, in some cases, moving to action: initiating such discussions with patients. That is, this was more than the *manner* in which these workers gave care to patients, but related to their actions (that is, the *content* of care); what they did, not (only) how they did it.

[2] George Lakoff and Mark Johnson (1980), *Metaphors We Live By*. Chicago and London: University of Chicago Press.

I will suggest that the distinction which I have made between the manner and the content of care is broadly equivalent to the distinction which Patricia Benner and Judith Wrubel make between what they call the "expressive" and "instrumental" dimensions of care.[3] It seems to me that the distinction between the manner (expressive dimension) and content (instrumental dimension) of care is particularly pertinent in relation to the spiritual aspects of care. "TLC" could perhaps be (and is sometimes) thought of as "expressively" "spiritual care," and is perhaps a necessary precondition for "instrumental" "spiritual care." However, some workers in St Z's suggested that "TLC" alone is not the entirety of spiritual care.

Although most workers in St Z's distinguished between religious and spiritual care, few could identify what made care specifically spiritual. I did not think that the spiritual aspects of care were not present in St Z's in any systematic way, neither expressively, nor (and even less so) instrumentally, and this was also the perception of many workers.[4] Instead, care with a spiritual content was delivered by the minority of workers who had a religious faith.

I did not take the understanding of spirituality and spiritual care which I outline in this chapter with me to my fieldwork, but rather developed it through doing my fieldwork, including my reflections on what I was observing, imitating and hearing. It is important to bear this in mind, because this chapter proceeds in a linear fashion, whereas (as I pointed out in the methodology chapter, and as applies to my thesis as a whole) my data collection and reflection on data (analysis) happened iteratively, and this chapter is the end result of this process.

EXPLORING THE SPIRITUAL ASPECTS OF CARE

As I noted in the previous chapter, in the early days of my fieldwork in St P's I became aware of a way in which certain workers (mostly, but not exclusively, nurses)

[3] Patricia Benner and Judith Wrubel (1989), *The Primacy of Caring: Stress and Coping in Health and Illness*. Menlo Park, California: Addison-Wesley.

[4] And also in the perception of management, who, shortly before I finished my fieldwork, employed a "pastoral care coordinator," PCC 24, specifically to focus on the spiritual aspects of care, for both patients and workers.

on this ward interacted with patients, which contrasted markedly with the "busyness" apparent on St E's and in day care. I (privately and provisionally) labelled this kind of interaction as spiritual. The carer was (or presented herself as being) not rushed, with lots of time to be totally focused on each individual patient, and with an attitude towards patients which I felt could best be described as loving.

In thinking about the quality of these interactions, I not only reflected on workers' interactions with patients, but also on my own interactions with workers, in particular my experiences when I was relatively new to St Z's. I thought about the workers with whom I felt most comfortable, and/or by whom I felt most welcomed, and considered why I felt this. This gave me some insight into how these workers (also) enabled patients to feel comfortable on the ward.

I initially thought that this kind of engaged interaction and focused attention could be considered to be spiritual care, because it seemed to me to express an attitude which could be thought of as spiritual,[5] and/or as stemming from something spiritual of or within the carer. As part of the participatory dimension of my fieldwork I tried to imitate the approach of those particular workers (for example, SN 16, SN 17) on St P's whose behaviour seemed to me to most often be of this kind. As I did so, my interactions with patients became more loving, and more rewarding

[5] Daphne Hampson ((1996), *After Christianity.* London: SCM Press: 260) argues that spirituality and ethics are interwoven, and discusses attention, honesty and "ordering" as spiritual/ethical practices. The concept of "attending" has been of increasing philosophical interest in recent years, and has been largely developed by women (as a result, Hampson suggests, of the social situation in which women have been the ones who have needed to attend to others). See for example Iris Murdoch ((1970), *The Sovereignty of Good.* London: Routledge and Kegan Paul) and her development, drawing on the work of Simone Weil ((1959), *Waiting on God.* London: Collins) of the concept of attention in moral philosophy. Murdoch's work has in turn been built on by various feminist moral philosophers, such as Sara Ruddick ((1989), *Maternal Thinking: Toward a Politics of Peace.* Boston: Beacon Press), Martha Nussbaum ('"Finely aware and richly responsible": literature and the moral imagination,' in *Love's Knowledge: Essays on Philosophy and Literature* (1990), Oxford and New York: Oxford University Press), Sarah Hoagland ((1988) *Lesbian Ethics.* Palo Alto, CA: Institute of Lesbian Studies) and Lawrence Blum ((1994) *Moral Perception and Particularity.* Cambridge: Cambridge University Press). Lorraine Code, a feminist philosopher of knowledge, also focuses upon attentiveness, which she calls "a passionate detachment" (Code (1988), 'Experience, knowledge and responsibility,' in Griffiths, M and M Whitford (eds.), *Feminist Perspectives in Philosophy*, Bloomington: Indiana University Press: 196). Finally, Peta Bowden ((1997), *Caring: Gender-Sensitive Ethics.* London and New York: Routledge: 109) claims that Patricia Benner's accounts of nurses' practical skills and involvement with their patients ((1984), *From Novice to Expert: Excellence and Power in Clinical Nursing Practice.* Menlo Park, California: Addison-Wesley) echo Iris Murdoch's account of attention.

for me, while patients also confided in me more. My participation thus gave me increased insight into the outcomes of these kinds of interactions.

In parallel with my early observations and participation – in this case, my attempts to imitate what I thought I observed – I was also conducting interviews with workers. As these various aspects of my fieldwork progressed, I began to reflect on the distinction and the relationship between the emotional and the spiritual aspects of care, and began to realise that, although I felt that some interactions between workers and patients were perhaps spiritual in *manner*, I did not feel that I could identify any aspect of the *content* of these interactions which was particularly spiritual (as distinct from emotional, for example). I wondered whether this was because such specifics would be hard for me to see as an observer, since care which had a spiritual content would probably be intimate and carried out in private, one-to-one interactions (although such care would possibly link to, and develop from, public interactions between people).

I therefore began to shadow the particular nurses I had provisionally identified as "spiritual carers," hoping that this would enable me to see care which had a spiritual content. However, I still felt that I was not able to observe such content. I thought that this could be because the presence of even one more person in an intimate situation changed the dynamic of the relationship between the patient and the nurse from one-to-one to one-to-many (regardless of whether the patient involved was someone with whom I too had developed a relationship through the course of my participation on St P's). I increasingly sought, therefore, to explore the spiritual aspects of care indirectly, through people's perceptions of them, that is, through talk (conversations and interviews) rather than observation.

It gradually became apparent to me that very few workers in St Z's, whether in public or in private (one-to-one interviews), were willing to say that there was such a thing as spiritual care. I often began my interviews with an open question along the lines of: "could we start by you telling me something about who you are and what you do here in St Z's?" Although my interviewees knew that my main interest was spiritual aspects of care, both because of daily conversations about my research ("what is it you're doing again?" and discussions in the nursing station and

elsewhere) and also specifically because of the information sheet and consent form which I asked each interviewee to read and sign immediately prior to the interview (Appendices II and III), few people volunteered that they felt that there was a spiritual dimension to their activities. However, when I specifically asked workers if they could define spirituality, they generally distinguished it from religion. This distinction is frequently made in the nursing literature generally, as well as specifically in the literature on hospice, but I suggest it was also in part associated with the acute awareness of religious affiliation amongst people in the West of Scotland. This awareness, as I noted in the previous chapter, meant that there was some sensitivity around overtly addressing religious questions – workers and patients in St Z's were generally aware of each other's religious affiliations (which they were often able to deduce from names[6] or from where people lived or had gone to school).

I also noted in the previous chapter that there were noticeable differences between the different parts of St Z's, and these differences were also evident in workers' talk about the spiritual aspects of care. Thus, while workers in day care were generally aware of and acknowledged the hospice philosophy of "total care," and its inclusion of spiritual aspects, they did not consider that spiritual care was part of what they did[7] in day care, nor (therefore) did they have a clear understanding of spiritual care.

In St E's, spiritual issues were not openly/publicly addressed between workers and patients, and one-to-one situations seldom occurred, owing to the low staff:patient ratio on this ward. In my conversations and early interviews with workers (for example, with SN 4, one of the sisters on St E's) most workers on this ward said or implied that spiritual care was indistinguishable from emotional care, and/or characterised spiritual care as attached, loving care for their patients, that is, as an attitude on the part of the carer, rather than as any particular content of that care.

[6] It was possible to deduce this both from people's surnames and, often, also from their first names, which, as I have noted, were used frequently in St Z's.

[7] As I noted in the previous chapter, workers in St Z's had a strong sense of their role boundaries, and of what was and what was not part of their job: "I'm not qualified."

Thus, AN 26 spoke about her feelings of attachment towards particular long-term elderly patients, while SN 2 responded to my question of what was spiritual care by saying: "you just love them (..) you just do."

SN 2 was a staff nurse on St E's, who was in her late 30s with three children. She had given up nursing when her first child was born, and had returned to nursing, in St Z's, a few years before I began my fieldwork there. She distinguished between palliative and elderly care, saying that she felt that in palliative care:

Transcript 5.01

	1	there's a barrier you put up to an extent but (.)
	2	with the elderly you can't (..)
	3	you can't put that barrier up
->	4	because you (.)
->	5	you just love them (..)
->	6	you just do
	[...]	
->	7	there's patients on St [*E's*] ward
->	8	°that I'll° (.)
->	9	°I'll just° (..)
->	10	°die off with them°
->	11	whenever they go

Note: the arrows in the margin of this transcript and the transcripts which follow indicate utterances which I discuss in the following text. Talk surrounded by degree signs – °talk° – indicates talk that is noticeably quieter than surrounding talk. See appendix V for other details of transcript notation.

SN 2 was the only nurse on St E's who told me that she thought that part of the care which she gave was spiritual, and by this she meant her loving attitude towards her patients. When I specifically asked other nurses on St E's (in conversations and/or in taped interviews) if they could identify any part of their care which was particularly spiritual, most responded by saying either that they could not do so, or that they felt spiritual care was "just good nursing practice" (by which they meant "TLC" and the integration of emotional and physical care).

SN 2 was therefore exceptional, and she elaborated on her understanding that her spiritual care was her attitude towards (that is, her *manner* of caring for) her patients, by telling me about her strong personal spiritual beliefs, from which her perception of spiritual care flowed. While telling me about this, however, she repeatedly stressed that what she was telling me was confidential, saying that she would never tell her colleagues that she thought of herself as giving spiritual care, nor discuss her spiritual beliefs with them. The interview I conducted with SN 2 took place very early in my fieldwork, and at a point when I had not observed many conversations between workers, but over time it became increasingly apparent to me that her remarks did not relate to something unique to her: workers did not discuss issues related to the meaning of death and dying amongst themselves.

Nurses from both wards took their breaks in the staff rest room downstairs in St Z's. At these times they occasionally spoke about their feelings about patients, and about the feelings of patients and their families, particularly those of younger patients with young families, making remarks such as "it's so sad," "it's hard [*for the family*]," "it's not fair." Some of these feelings might have spiritual implications, but nurses did not explore those feelings, nor the underlying issues, further. They acknowledged their own and each other's feelings, but went no further in discussing the implications of these for the meaning of life, and their understandings of life and death (that is, they did not discuss their spiritual, religious, existential or metaphysical[8] beliefs with each other).[9]

I noted this feature of staff room interactions before I began fieldwork on St P's, and I wondered whether a factor in this was that the nurses on St P's were working with patients whose situation was very different from that of the majority of patients on St E's, so that issues and meanings associated with death and dying came

[8] It could be considered that these terms address similar issues, and possibly that they overlap. Existential seems to me to be the most neutral, encompassing term, although precisely in its neutrality it may be taken to deny the existence of "spirit." I will therefore usually use the phrase: "spiritual or existential."

[9] Similarly, while psychological/emotional issues were acknowledged in case conferences, extended discussion of these issues was rare, and existential/spiritual issues even more so.

up more frequently for them, and had different implications when they did.[10] Thus, I wondered whether nurses from both St E's and St P's might avoid discussing these issues in a group which included nurses from both wards. My presence could also have been a factor which inhibited such discussion (although it did not inhibit discussion of emotions). Whatever the reason, however, and perhaps paradoxically, although St Z's was a Catholic hospice, workers in St Z's did not openly discuss religious, spiritual or existential issues with each other in my presence. I wondered whether workers discussed these issues with one another on a one-to-one basis (as I also wondered about workers and patients), or when they were together on their "own" wards.

However, many nurses on St P's, similarly to most nurses on St E's, told me that they thought of what they did as "good nursing care" or "real nursing," which included "TLC," but that they did not consider that spiritual care was part of this, nor that nursing included spiritual care. As I noted in the previous chapter, many nurses on St P's said that they had been attracted to working in St Z's by the opportunity it offered for them to do "real nursing." Few nurses said that they felt that they had been particularly "called" to care for dying people,[11] and few told me that they had spiritual beliefs or practices (whether personal or professional). SN 2 was thus exceptional not only for St E's, but for both wards, although a few nurses on St P's did tell me that they felt that "TLC" was both emotional and spiritual care.

As I noted in my methodology chapter, time and other constraints meant that I could not interview everyone in St Z's. I therefore had to select a group of workers to interview. At the outset of my fieldwork I planned to interview a cross-section of all the workers in St Z's, so I selected people to interview on the basis of the job they did. As I found that few people, whatever their job, claimed that spiritual care existed, let alone that they carried it out, I decided to specifically interview two

[10] As I discussed in the previous chapter, the relatively long stays of most patients in St E's meant that the relationships between them and workers were long-standing: "you spend more time with them than your own family."

[11] Unlike workers in the early days of the modern hospice movement (see Nicky James and David Field (1992), 'The routinization of hospice: charisma and bureaucratisation,' *Social Science and Medicine*, 34 (12): 1363-75).

groups of people: those workers who I had provisionally identified as possibly providing spiritual care, and those workers who were cited by other people (when I asked them) as examples of people who gave spiritual care.[12] I will now discuss some of the issues which arose in these interviews, focusing first on how, although everyone in this selective group of people said that spiritual care existed, most struggled to define it. (Note that, because of the above, the following discussion relates to a small group of St Z's workers, not the majority).

Problems with articulating or defining spiritual care

HCC 11 was in her mid-late 40s, married with 2 adult children. She had worked on St P's for about 10 years, the last few as sister, but had left about a year and a half before I began my fieldwork to become a "Macmillan nurse" (providing palliative care for people living at home). A few months after I began my fieldwork she returned to St Z's to set up and run the new hospice home care service. Shortly before I finished my fieldwork she became the deputy matron (after Sr 13's return to London). I interviewed HCC 11 relatively soon after she returned to St Z's, so at the time of our interview I had not had much contact with her, nor had I spoken much about her with other people. However, subsequently, people (for example, SN 17 (see below)) identified her to me as someone who gave spiritual care.

[12] There are two main points to note in relation to this. Firstly, there was a significant overlap between these two groups, such that members of the first group were often (although not always) also members of the second group. Secondly, it is of course possible that by selectively interviewing people in this way, I missed some people who were also "spiritual carers," since when I interviewed SN 2, I had not identified her as a "spiritual carer." However, I interviewed SN 2 relatively early on in my fieldwork, before I began selecting interviewees on this basis. Nevertheless, nobody later indicated to me that they felt that SN 2 was a "spiritual carer." However, by the point in my fieldwork when I had begun selectively interviewing I was spending time on St P's, where SN 2 did not work. In any event, I would have been unable to interview everyone in St Z's. I did, however, interview (all the) key religious people in St Z's: both nuns: Sr 8 (the matron) and Sr 13 (the deputy matron), (although neither of them had much involvement with patients, since their professional roles meant that they interacted more with staff) (and, interestingly, nobody cited them to me as "spiritual carers"). I also interviewed Rev 19 (the (female) Church of Scotland minister), Fr 18, one of the priests who came to St Z's regularly to conduct services (and also at other times, when a patient specifically asked to see him), and PCC 24. The care these religious people provided could be spiritual as well as religious, but this was not necessarily the case. So, for example, although Fr 18 distinguished between religious and spiritual care when talking theoretically, when he gave me examples of spiritual care he effectively collapsed spiritual care into religious care.

HCC 11 had been talking about people's need for physical touch, and commented that she felt that people "opened up" in intimate situations such as when they were given a bath. I asked her:

Transcript 5.02

	1	**me**: [...]
	2	would you say (..)
	3	would you say there was such a thing as spiritual care?
	4	**11**: mmhm
	5	**me**: an' and (..)
->	6	**11**: I'm **ver**y much into the spiritual and religion are not the same...
	7	and nurses (..)
	8	we're still quite awful
	9	you know when you talk about spirituality because we (..)
	10	umm (..)
->	11	they're now doing care plans and there's boxes for spirituality
->	12	and we found if you look
->	13	somebody'll have written RC [*Roman Catholic*]
->	14	and you think oh *God* you know (..)
->	15	that's not really (.)
->	16	what we're talking about (..)
	17	**me**: and do you (.) sorry just (..)
	18	when you're talking about care plans (.) do you have (..)
	19	I know (.) some places have (.)
	20	take what they call a spiritual history when somebody's admitted
	21	do you do anything like that or?
	22	or I mean is it as far as (.) that's as far as it goes? (..)
	23	**11**: err (.) no we (..)
	24	now I haven't looked since I came back properly [*to St Z's*]
	25	but when I left we were working on care plans
	26	and there was a section (..)
	27	umm (..)
->	28	now how did we phrase it? cos we were really struggling (..)
->	29	it was spirituality stroke what helps you to cope (..)
	30	was going to be the box and I think that's how it was when I left
	31	and I don't know what they've done since (..)
	32	but (..)
->	33	I think we sort of felt that some people (..)
->	34	still make a connection between spirituality (..)
->	35	and religion
->	36	and if you asked them what they needed spiritually they would say
->	37	oh I want the priest I want the minister (.)

-> 38 or I *don't* want the priest I *don't* want the minister (.)
-> 39 but there'd still be (..)
-> 40 there's still a lot of (?other things) you know (.) there (.)
-> 41 and it was trying to get the difference and the balance and (..)
-> 42 we were **try**ing to focus on the idea (..)
-> 43 from a nursing point of view as well (..)
-> 44 that although somebody said oh I don't have spiritual needs yes they *did*
-> 45 that there were things that they would **need** to help them (.) cope (.)
-> 46 and deal with the situation (..)
-> 47 trying to make everybody aware of what (.) what it was (.)

48 **me**: so so that's how you (.) so spiritual needs are (..)
-> 49 it's something about how people (.)
-> 50 how people find a way of coping with what's happened to them?

-> 51 **11**: and their beliefs and values

[**me**: right

52 umm (..)
-> 53 I think it's all intertwined again it's very difficult to separate
54 I mean for some people their spirituality is purely a religious thing
55 umm but I don't think for the majority of us that it is
-> 56 I think our spirituality is *dee*per (..)
-> 57 and it's the things that (..)
-> 58 we be**lieve** in and that enable us to be ourselves
-> 59 and to cope with (?today) an' everything else (..)
60 we all sort of draw on different (..)
61 things (..)

62 **me**: mmm, mmm
-> 63 and what's the difference between that and emotional (..)
-> 64 need?
-> 65 this is one of these questions that I said at the beginning may may be (..)

-> 66 **11**: can I come back in a week and tell you? ((laughs)) (..)
-> 67 umm (..)
-> 68 emotional or spiritual needs (..)
-> 69 I think sometimes somebody's emotional needs umm (.....)
-> 70 well you see sometimes you just have to listen
71 and you can make someone (..)
-> 72 but then again that can be spirituality as well
-> 73 I'm struggling (.) umm (.....)
-> 74 I don't know I'm really struggling at the moment (..)

[**me**: mmm

-> 75 umm I think there are **levels** and I'm finding it very difficult (..)
76 I mean I said they were separate I mean and I **do**

77 if I'm doing anything on (..)
78 palliative care I say emotional psychological and spiritual needs
-> 79 I do (..)
-> 80 differentiate them

[**me**: mmm

-> 81 but I think (..)
-> 82 separating them when you're looking at a patient would be very difficult

Thus, like most nurses in St Z's, HCC 11 distinguished between spiritual and religious needs. She also said that a person's religious needs may be met yet their spiritual needs may still remain, and argued that people have spiritual needs even if they say they don't. However, despite being clear that people's spiritual needs were distinct from their religious, emotional and psychological needs (although she defined spirituality as relating to "coping" – lines **29**, **45** and **59**), HCC 11 "struggled" to define the characteristics of these needs. Her difficulty was evident in her frequent pauses and "umm"s (see particularly lines **66-73**), and also expressed more explicitly, such as in her repeated use of "struggling" and reiterations of "very difficult":

line **28**: we were really struggling

line **53**: I think it's all intertwined again it's very difficult to separate [*spirituality and other things*]

lines **73-75**: I'm struggling umm (.....) I don't know I'm really struggling at the moment, umm I think there are **levels** and I'm finding it very difficult (..)

lines **79-82**: I do (..), differentiate them [*emotional, psychological and spiritual needs*], but I think (..) separating them when you're looking at a patient would be very difficult

I will comment on "very difficult" in more detail below (following transcript **5.04**) and I will also return later to HCC 11's comment (line **56**): "I think our spirituality is *dee*per [*than religion*] (..)".

Here I would like to make two interactive, methodological points. First, in lines **63-64** I asked HCC 11 what the difference was between spiritual and emotional need. I began to specifically ask this kind of question of those of my interviewees who said that they could identify spiritual needs/care, as I became more interested in

how people distinguished between emotional and spiritual care, and how they related these (also see lines **7-8** in transcript 5.03 which follows). Second, in line **65** I am referring back to my introduction to the interview, when I said to HCC 11 that she might not necessarily be able to answer some of my questions, but that that was not a problem, and that there were no right or wrong answers. Again, I did this increasingly as I began to notice the problems which many of my interviewees had with articulating issues around spirituality.

SN 17 was a staff nurse in her mid 20s, who was one of the younger children in a (Catholic) family of 8 children and still lived at home with her parents. She had first come to St Z's as a nursing student, and had returned when she qualified, and had been there for 3 years when I interviewed her. She was someone I had identified as having a quality to her interactions with patients which I thought of as spiritual in manner. She was very focused on and gentle and loving towards patients, and I also found her to be like this in her interactions with me. She was also someone who other people identified to me as perhaps giving spiritual care. We had spoken for a while about how she had come to St Z's and what she felt she did in her work, and then:

Transcript 5.03

((we both started to talk simultaneously))

	1	**me**: go on (..)
	2	**17**: no it's ok you were going to ask me a question
	3	**me**: well I was in- (..)
	4	because I'm interested in this idea of spiritual pain and (..)
	5	would you? (..)
->	6	and one of the things that interests me is how (..)
->	7	or **if** there's a distinction between emotional pain and spiritual pain
->	8	and how (.) if there **is** a distinction (.) how you would make it?
->	9	**17**: (.....) difficult Bella isn't it? (.....)
->	10	emm (..)
->	11	do you think that emotional (.) emotional pain is more umm (..)
->	12	how they're feeling themselves and how they're coping with it themselves?
->	13	(.) emm (..)
->	14	and (.) thinking about the distress that it's causing an' (.) emm (.)
->	15	you know their lives are really sort of torn apart (.)

-> 16 they're losing a loved one (.)
-> 17 whereas (..)
-> 18 spiritual pain's more (..)
-> 19 it's that sort of why an' (..)
-> 20 you know what if (..)
-> 21 emm (.....)
-> 22 you've always been (.) always been *good* an' al- (..)
-> 23 you know (.) they've been there for the church or whatever emm (..)
-> 24 and why's this happened to them (.)
-> 25 it's that (.) is it that sort of distinction where emotion is more? (..)

26 **me**: mmm I don't want to tell I want (.) [**17**: I (.)
27 I don't want to tell you I want you to tell me [**17**: I know
28 ((laughs)) [**17**: ((laughs))

29 **17**: so that (.) that would be the kind of distinction that *I* would make

30 **me**: mmm (.) mmm (.)
-> 31 so in terms of care-giving (..)

[**17**: mmm

-> 32 emotional care and spiritual care (..)
-> 33 who (.) who gives (.) who gives which kind of care and (..)
-> 34 what is the nature of that care?

-> 35 **17**: (.....)
-> 36 I think well we all (.) we all do don't we?
37 yeah (..)
38 emm (..)
-> 39 oh it's difficult Bella
-> 40 it's difficult to make the distinction and to to say who provides what

[**me**: mmm

-> 41 emm (..) I don't know (.)
-> 42 could you ask me another question ((laughs))
-> 43 that would (.) I don't know (.) I really (..)

-> 44 **me**: ok (.) umm (.....)
-> 45 how can I? (.....)
-> 46 when you (.) when you say everybody does it (..)
-> 47 umm (..)
-> 48 do you think when somebody is in that kind of distress
-> 49 and saying why me (..)

-> 50 **17**: I think what I mean to say is all members of our team (..)
-> 51 emm (..)
-> 52 are conscious of it (..)

-> 53 we're always we're always sort of picking up on different points emm (.)
-> 54 patients (.)
-> 55 some patients relate better to other mem (.)
-> 56 to some members of staff than they do to others

[**me**: mmm

-> 57 some members of the **fa**mily relate better to different members of staff
58 emm (..)
-> 59 an' we're always (..) (.....)
-> 60 so I think everybody's (.) everybody's conscious of it

[**me**: mmm

61 you know

[**me**: mmm

62 emm (..)
-> 63 where they are sort of emotionally (..) emm (..)
-> 64 spiritually it's different (..)

SN 17 began line **14**, line **19** and line **22** with "you know," but did not wait for me to respond. Nevertheless, she ended her utterance in lines **19-24** with a question, which seems to me to suggest that she wanted dialogue with me. However, I was trying *not* to have a conversation, and, specifically, not to suggest answers to her, see the "you tell me" interaction in lines **26-27**; and open questions which I ask in lines **7-8** and lines **31-34**, and begin to ask in lines **48-49** (interrupted by SN 17, who is continuing to try to answer my previous question). Also note line **42** where, as she struggles to respond to my question of whether she can distinguish between emotional and spiritual care, SN 17 asks me to ask her a different question.

I then asked SN 17 if it would be easier for her to distinguish between emotional and spiritual care by giving me an example of someone who gave spiritual care. She said HCC 11, and I asked her whether she could give me any examples of how HCC 11 did this; SN 17 responded:

Transcript 5.04

-> 1 **17**: oh:h I'm terrible amn't I? I don't (..)
-> 2 I find it really difficult to think think of (..)
-> 3 emm (..)

-> 4 kind of (..)
-> 5 spirituality an' what [*HCC 11*] provided that's (..)
-> 6 spiritual (..)
-> 7 you know (..)
-> 8 °I suppose° (..)
-> 9 °°different°° (..)
-> 10 I need to sit down and think about it (..)
-> 11 it's not (..)

-> 12 **me**: you see you say it's [**17**: it's (..)
-> 13 it's terrible that you can't think of it but you see **I** think
-> 14 that's the **na**ture of it [**17**: mmhm
-> 15 that it's difficult [**17**: mmhm
16 so (..) [**17**: mmhm
17 you know (..)

-> 18 **17**: it's easy Bella to define you know spirituality in in emm (..)
-> 19 you know kind of religion religious issues that come up you know that (..)
-> 20 but it's different (..)

[**me**: mmm

-> 21 mmhm (..)
-> 22 I find it (..)
-> 23 did you find that (.) do most people find it quite difficult?

24 **me**: I don't no I
25 I mean not *most* people **e**verybody
26 I don't think **any**body's come up with a kind of (..)
27 this is what it is an'
28 I know who does it an' you know
29 and and you
30 and that's kind of (..)

31 **17**: because I'm thinking to myself
32 I'm sure she probably *did* provide you know spiritual (..)
33 support as [**me**: [*HCC 11*]?
34 as well as emotional support ((nods))
35 you know
-> 36 but to sit down and pinpoint what she actually did to provide it
-> 37 then (..)
-> 38 that's
-> 39 that's the difficult part (..)
-> 40 do you think just (..)
-> 41 just being there an'
42 being on (.) you know
-> 43 being there an'(..)
44 understanding what's happening an' (..) emm (..)
-> 45 I suppose that's even providing spiritual support isn't it?

-> 46 **me**: mmm and
-> 47 not running away

-> 48 **17**: not running away yeah
-> 49 mmhm
-> 50 mmhm
-> 51 facing
-> 52 you know (..)
-> 53 putting your hand up and saying I *can't* answer the questions (..)
-> 54 you know

-> 55 **me**: but I'm not scared
-> 56 that you're asking these questions

-> 57 **17**: that's right
-> 58 that's right
59 emm (..)
60 and she
61 she wasn't (..)
-> 62 a lot of the time you know (..)
-> 63 it's it *is* really easy just to keep things (..)
-> 64 emm (..)
-> 65 you know conversations to emm you know
-> 66 °°did you (?) or (?) today or°° (..)
-> 67 cos you know if you **do** get in you know
-> 68 deeper an' deeper then it gets harder and harder an' (..)
69 emm (..)
70 but she was [*HCC 11*] always had the time so yeah
71 she probably did provide (..)
-> 72 °°sort of spiritual°°
-> 73 °as well as emotional an'° (..)
-> 74 mmm is that a bit more clear? ((half-laugh))

-> 75 **me**: when you say if you get
-> 76 as you get deeper it gets harder

[**17**: mmhm ((half-laugh))

77 umm (..)

-> 78 **17**: Bella I need to watch what I'm saying here ((laughs)) [**me**: ((laughs))
79 no (.) but you do (.) you (..)
80 you know (..)
81 emm (..)
-> 82 if you go an' have a conversation with somebody an'
-> 83 hiya how're you doing how did you enjoy your meal see you later (..)
84 you know (..)
85 and I'm here if you need me for anything (..)
-> 86 that's **ea**sy to do (..)

[**me**: mmm

-> 87 °if you sit down and you spend time with somebody°
-> 88 °the conversation you know becomes° (..)
-> 89 goes down to a deeper level an' you know they maybe get emotional (..)
-> 90 you know become quite distressed or (..)
91 emm (..)
92 and they'll start to ask questions (..)
93 you know ((ttt)) want reasons for different things

[**me**: mmm

94 you know (..)
-> 95 a lot of people [*staff*] find that they *can't* cope with that you know
-> 96 that they will keep things to emm (..)
-> 97 a basic conversation

[**me**: mmm

-> 98 whereas (..)
-> 99 emm (..)
-> 100 [*HCC 11*] was never frightened of anything like that

Note: the laughter around lines **75-78** reflects first SN 17's and then my awareness of the sexual double entendre in my repetition (line **76**) of what she had said (line **68**). Also note SN 17's repeated use of my first name (lines **9** and **39** in transcript 5.03 and lines **18** and **78** in transcript 5.04). As I mentioned above, use of people's first names when addressing them was a striking feature of the talk of many workers in St Z's.

As with HCC 11, SN 17's frequent pauses and repetitions of "emm" and "you know" (see particularly **1-11** and **57-73**) indicate her difficulty with articulating these issues. Marjorie Devault argues that "you know" signals a request for understanding, and is thus part of the joint work of a conversation.[13] Similarly, Carol Gilligan asserts that when a speaker says "don't know," this serves partly to test the relationship, and what the speaker can safely say to the listener.[14] Devault claims that women who are

[13] Marjorie Devault (1990), 'Talking and listening from women's standpoint: feminist strategies for interviewing and analysis,' *Social Problems,* 37 (1): 96-116: 103.
[14] Carol Gilligan (1992), 'Getting civilized,' pp. 13-28 in Oakley, A and J Mitchell (eds.), *Who's Afraid of Feminism: Seeing Through the Backlash.* Harmondsworth: Penguin: 20; 22.

trying to translate their experiences into words often use "you know," and that this phrase illustrates the inadequacy of everyday speech for describing women's experiences, since, while women know what they mean, they don't have the words to say it exactly; expressing or articulating their thoughts may be new for them. Thus, Devault argues that women who use "you know" are indicating that they don't know how to verbalise what they know[15] (compare Gilligan's claim that "don't know" is a marker for areas of knowledge which the knower is protecting from attack).

I suggest that Devault's claim applies to all kinds of marginalised, excluded or unspoken knowledges, not only women's. In this case, it applies to knowledges about spiritual issues (which (also) happen to be voiced by women). My interviewees' repeated use of "you know" can be taken as indicating both their attempts to articulate something which they were not used to verbalising, and also their repeated testing of me, including implicit requests for my understanding. Perhaps they were also seeking to recruit me in constructing the concept.

Thus, like HCC 11, SN 17 indirectly expressed her difficulty with articulating her knowledge. She also (again like HCC 11) expressed her difficulty explicitly, in her repeated use of the word "difficult" itself. Thus, in transcript 5.04:

lines **2-6**: I find it really difficult to think think of (..) emm (..) kind of (..) spirituality an' what [*HCC 11*] provided that's (..) spiritual (..) you know (..)

lines **18-23**: it's easy Bella to define you know spirituality in in emm (..) you know kind of religion [...] but it's [*spirituality is*] different [...] I find it (..) did you find that (.) do most people find it quite difficult?

lines **36-39**: but to sit down and pinpoint what she actually did to provide it [*spiritual support as well as emotional support*] then (..) that's that's the difficult part (..)

Although SN 17 found explicitly defining spirituality or spiritual care difficult,[16] however, she still had a sense (again, similarly to HCC 11) that "depth" was

[15] Devault (op. cit., note 17: 102).

[16] Note that in lines **12-15** and lines **24-30** I was trying to reassure SN 17 that her sense that it was difficult to talk about spirituality was not a bad thing. In my attempt to encourage her, while not prompting her, and in trying to express my sense of the difficulty she was finding in being precise in her talk, I was equally imprecise.

associated with these issues. She linked the phrases "get in" and "goes down" with her sense of depth: lines **67-68**: "if you **do** get in [...] deeper," and lines **88-89**: "the conversation [...] goes down to a deeper level."

lines **62-66**: a lot of the time you know (..) it's it *is* really easy just to keep things (..) emm (..) you know conversations to emm you know, °°did you (?) or (?) today or°° (..), cos you know if you **do** get in you know, deeper and deeper then it gets harder and harder an'(..)

lines **87-93**: °if you sit down and you spend time with somebody,° °the conversation you know becomes° (..) goes down to a deeper level an' you know they maybe get emotional (..) you know become quite distressed or (..) emm (..) and they'll start to ask questions (..)

Thus, for SN 17, talking about spirituality and spiritual care (to me) was difficult, and this was evident in that her voice became noticeably quieter when she spoke about conversations going "deeper" (lines **66, 88-89**), perhaps indicating her uncertainty with what she was saying, as well as (as discussed) in her frequent pauses and utterances of "emm" and "you know" and her explicit comments of "difficult." SN 17 did not only use "difficult" in relation to talking with me, she also used the same idea of difficulty when she spoke about workers' attitudes towards patients' "deep" issues, frequently contrasting "hard" and "easy":

lines **82-86**: if you go an have a conversation with somebody an' hiya how're you doing how did you enjoy your meal see you later (..) you know (..) and I'm here if you need me for anything (..) that's **ea**sy to do (..)

lines **95-97**: a lot of people [*workers*] find that they *can't* cope with that you know, that they will keep things to emm (..) a basic conversation

lines **98-100**: whereas (..) emm (..) [*HCC 11*] was never frightened of anything like that

Thus, SN 17 said that she felt that workers found it hard to have "deep" conversations with patients, conversations which were perhaps similar to the conversation she was having with me. She felt that workers found it easier not to have such conversations with patients, and that workers resisted doing so: lines **63**: "it *is* really easy just to keep things (..)" and lines **96-97**: "they [*workers*] will keep things to emm... a basic conversation." SN 17's repeated phrase "keep things"

indicates her sense that workers actively controlled conversational topics, keeping conversation "basic" (at surface level) rather than going "deep." This perception that workers consciously chose whether and how they engaged with patients echoed my observations on the wards and in day care of how some workers actively avoided engaging with patients' "deep" issues, choosing instead to "jolly" patients along, as in line **83**: "hiya how're you doing how did you enjoy your meal see you later."[17]

In transcript 5.04 it might appear that I am prompting SN 17 when I mention people being scared of (lines **55-56**) and "running away" from (lines **46-47**) "deep" conversations. However, this interview was conducted relatively late in my fieldwork and was one of a series of conversations (one which happened to be tape-recorded) which SN 17 and I had had around this theme, and I was re-presenting to her things which she had said to me previously. In lines **98-100** SN 17, unprompted by me (although possibly referring back to my earlier comments), contrasts ("whereas") what she had just said about workers who "keep things" "basic" with HCC 11's "never" being "frightened." Thus SN 17 returns to her sense that addressing "deep" issues may evoke fear on the part of workers.

My interviews with HCC 11 and with SN 17, similarly to my other interviews with "spiritual carers," convey how even those people who said that they thought of themselves as providing spiritual care, and/or who others identified as doing so, found it hard to articulate what was specifically spiritual about what they did. This could have been because they did not want (chose not) to talk to me about these issues, but it did not seem to me that this was the case. Rather, it seemed to me that my interviewees tried to talk with me about such issues, but were unable to and/or found such talk problematic. It seemed to me that my interviewees wanted to help me, and give me the detailed, explicit definitions and descriptions of spiritual care which they thought I wanted. Several of my interviewees apologised to me for not having an answer ready; see SN 17's remark: "oh:h I'm terrible amn't I?" (transcript **5.04**, line **1**). This seemed especially apparent in the later interviews, which were

[17] I will return to "how're you doing" when I discuss Sr 13's use of "how are you" later in this chapter.

conducted after I had been at St Z's for some time, so some trust had been built up between me and the people I was interviewing.

I think that the marked problems these interviewees had in articulating their concepts of spiritual care lay at least in part in their lack of a language with which to do so. Their problems with talking about spiritual care does not of itself necessarily mean that they did not *give* such care. However, the lack of fluency of most of the people I interviewed suggests that they were not practised in articulating issues around spirituality, that is, that they were unused to talking about spiritual issues. The general silence around religious/spiritual issues, and absence of any public discussion of spiritual or existential issues, amongst workers in St Z's could well have had consequences for whether they spoke about spiritual issues with patients (which, again, their lack of fluency suggests that they did not do). Their lack of fluency also implies that they did not usually discuss these issues outwith the hospice either.[18]

Spirituality and spiritual care: metaphors of location and movement

In the previous chapter I discussed how workers and patients used DOWN metaphors when they spoke about someone who they thought was getting closer to death: "he's going down lately;" "she's going downhill." I also showed how the metaphors of location and movement which people in St Z's associated with death and dying were paralleled by the significance which both workers and patients attached to patients' physical location within and movement between the distinct spaces within St Z's.

I illustrated above that even those few workers in St Z's who said that spiritual aspects of care existed found it difficult to tell me what they were. However, people who spoke about spirituality with me generally used words such as: "deeper," "beneath" or "beyond." These depth- and/or distance-related metaphors resonated with the metaphors of movement elsewhere (usually downward) which people in St Z's used to speak about patients who they thought of as approaching death. That is, workers in St Z's used a language of elsewhere to talk about both

spirituality and death, locating spirituality, like death, somewhere else; somewhere which was deeper than, beneath or beyond everyday life, including everyday physical or emotional experiences. Thus, SN 17 (transcript 5.04) commented on workers "getting in" "deeper and deeper" in conversations with patients, and her sense that such conversations "go down" "deeper," and HCC 11 (transcript 5.02) remarked that there were "levels" of psychological, emotional and spiritual need, and that "our spirituality is deeper." This sense that spirituality was not "here" but elsewhere was also conveyed in workers' talk about spirituality being something which was "left behind," or which was "inside" or "beneath the skin," as expressed by, for example, Dr 5 and SN 16.

Dr 5 was a male doctor in his late 40s; he was the senior consultant at St Z's, and had been the only consultant there for the first twelve years of the hospice. He was an anaesthetist, and said that it was his interest in chronic pain which had brought him into hospice care. Dr 5 would not let me tape our interview ("I've got a thing about tape recorders") (although at the end of the interview he expressed regret about this), so the text which follows is not transcribed from a tape recording, but is instead an assembly of direct quotes from notes which I took during the interview.

Transcript 5.05

	1	**me:** is there anything particular you think you contribute as an anaesthetist?
->	2	**5**: physical symptoms, including pain, need to be controlled
->	3	before you can get to other needs.
	4	If you get good pain control, everything else follows.
	[...]	
	5	**me:** and if you were to define the spiritual, how would you?
->	6	**5:** what you're left with when all worldly things are stripped away.
->	7	The pragmatic, material things drop off when people are in a crisis situation.
->	8	The soul is laid bare.
	[...]	
	9	**me**: and how would you define spiritual care?

[18] For workers who perceived spiritual care as an attitude, that is, their particular manner in their interactions with patients, spiritual care would not be expressed verbally.

-> 10 **5**: [...] Spiritual care means leading someone to understand themselves.
-> 11 Strip away the ego side,
-> 12 let them understand that they are on a journey to death,
13 as gently as possible.
14 Bring in the family too.
15 We try, though we don't always succeed, to do that,
16 to give the patient quality, peace and contentment.
17 Religion is a part of spirituality, but not the entirety.
18 Letting them know that death is not terrible, allaying their fears.

19 **me:** would you make a distinction between emotional and spiritual care?

-> 20 **5:** emotion can be very superficial
-> 21 relieving the pain of the family by bringing them in.
-> 22 Perhaps there is ego, a thin layer of emotion and a deeper spiritual self.
-> 23 Getting beneath the skin.
-> 24 You can see the ego coming back when there is a small improvement.

Thus, similarly to the other interviewees I have cited, Dr 5 spoke about "the deeper spiritual self" (line **22**), and his talk was full of these kinds of metaphors of location and movement, such as when he speaks of spiritual care as "getting beneath the skin" (line **23**). A similar sense of the spiritual being beneath something else is present in Dr 5's remarks: "when all worldly things are stripped away" (line **6**); "strip away the ego side" (line **11**),[19] and in his distinction between a surface and what is beneath it: "what you're left with," "material things drop off" (line **7**) (implying that material things are on the surface of a person) and "the soul is laid bare" (line **8**) (the soul is beneath something else).[20] Dr 5 was the only one of my interviewees who spoke of patients being "on a journey to death" (line **12**), a metaphor which links to the other JOURNEY metaphors which he used: "leading someone to understand themselves" (line **10**) and "bringing them [*the family*] in" (line **21**).

For Dr 5, physical symptoms needed to be "controlled before you can get to other needs" (lines **2-3**). Thus, for Dr 5, the material (physical) was on the surface of a person, and physical needs had to be addressed before getting beneath them – getting to somewhere below the surface, the immediate or the here-and-now. However, Dr 5 did not consider that "getting beneath the skin" was part of his role.

[19] Note the slightly violent imagery of "stripped away."
[20] Also note "see the ego coming back" (line **24**).

He told me that spiritual care in St Z's was carried out by "the nuns and some very good nurses," stating that "there are some brutal nurses out there" (that is, in places other than St Z's), and highlighting the importance of employing caring nurses.

Dr 5's perception that physical symptoms had to be addressed first was evident in case conferences, which, as I showed in the previous chapter, focused predominately on patients' physical issues. SN 16 also expressed this sense that physical symptoms had to be addressed first, before getting to the spiritual issues which underlay them.

SN 16 was a part-time senior staff nurse who was in her mid-40s, and married, with two teenage children. She (like HCC 11) had left nursing when her children were small to look after them full-time at home and had returned to nursing a few years before I began my fieldwork. SN 16 said that when she decided to return she had found herself attracted to palliative care, although she did not know why this had been the case. She had been working on St P's for several years by the time I began my fieldwork. Early in our interview, we had been talking about Jimmy M and her close relationship with him, and SN 16 said:

Transcript 5.06

	1	I think it's really just a matter of time
	2	to get tuned in to that person that you're looking after
	3	I suppose the longer you have then the more you get (.)
	4	the more opportunity there is to get to understand what's going on for them
	5	**me**: and would you (.) would you call that (.)
	6	is that spiritual care? (..)
	7	or would you call that emotional care? (..)
	8	or would you make a distinction between them (.) between the two?
->	9	**16**: I find it (.)
->	10	very hard (.) I've never really read (..)
->	11	a (?) definition of spiritual care or spirituality (..)
->	12	or people have different ideas of what it's all about umm (..)
->	13	one of the things that I read was umm (..)
->	14	what was it (..)
->	15	it was (..)
->	16	it was (.) what was **left** after everything else had been taken care of (.)
->	17	so if you had a patient who came in with a lot of pain an' (..)
->	18	various uncomfortable symptoms (..)
->	19	it was what was left after those were all removed

-> 20 when you still had a *per*son there (..)
21 and (..)
-> 22 and that it's *fee*lings it's to do with feelings an' thoughts an'
-> 23 everything that goes on in*side* I think (..)

[**me**: mmm

24 that's what **I** (..)
25 I've come to the conclusion that that's (..)
-> 26 it's often related to religion I think
-> 27 but I don't think that's (..)
-> 28 well it's (.) in my understanding of it I don't think (..)
-> 29 I mean it *can* be religion *and* spirituality I think (.)
-> 30 if that's what the patient is *com*fortable with (.)
-> 31 or if that's where they're *co*ming from (..)
-> 32 but it (.) in many people (..)
-> 33 in many people there is religion *al*so

[**me**: mmm

-> 34 but in many people there's *not*...

[**me**: mmm

-> 35 it's umm (..)
-> 36 but there's (.) there's still something there that's *them*

-> 37 there's (.) there's still this part of them which is (.)
-> 38 kind of intangible and it's just (..)
-> 39 umm their *mind* I think perhaps (..)

[**me**: mmm

-> 40 their thoughts an' their (.) their feelings (..)

Here, again like other workers, SN 16 distinguished between religion and spirituality, and for her, like the other interviewees I have discussed, spirituality was something inside, beyond or beneath the surface of, a person/patient:

line **16**: what was **left** after everything else had been taken care of

lines **19-20**: what was left after [*pain and uncomfortable symptoms*] were all removed, when you still had a person there (..)

line **23**: everything that goes on in*side* I think (..)

line **37-38**: this part of them which is (.) kind of intangible

This sense of these workers that spirituality was located somewhere else was associated with the suggestion that action and/or movement (some kind of change) were necessary to "get to" a person's/patient's spirituality. One kind of change (action or movement) which these workers repeatedly mentioned was the development of a particular kind of relationship between the carer and the person they were caring for.

Following on from what SN 16 had said, I asked her whether, given that she thought that spirituality was about a particular person's mind, she thought that spiritual care was different for everybody. She agreed, and I continued:

Transcript 5.07

	1	**me**: so that's quite a a skill to tune in to (.)
	2	what it is for this particular person (.)
		[**16**: mmm
	3	and what it is for this particular person at this particular time?
	4	**16**: **yes** (.) it changes all the time (.) it's different
	5	I mean (.) you know take a- any two people (.) they (..)
	6	it is err yes it is
	7	I suppose it *is* a skill to try to tune in
->	8	and you need a bit of time an' but you need *close*ness
->	9	you need to work *close*ly with somebody
->	10	and also for somebody to share anything which is err (..)
->	11	you know deeper than than just their usual (..)
->	12	chat (..)
->	13	there has to be some kind of closeness (.) doesn't there?
	14	with anyone
	15	it's like any (.) any two people (..)
	16	sharing something (.) you know (.)
->	17	they have to be on a certain level together (.) you know (..)[21]

Here, again, the metaphor of depth is important; like my other interviewees, SN 16 used words such as "deeper" and being "on a certain level," which indicated her sense of the location of spirituality and of the consequent movement which she associated

[21] In relation to my earlier discussion of "you know," note SN 16's repeated cross-checking with me: "you know" lines 5, 16, 17 and "doesn't there?" line 13.

with spiritual care, that is, a movement to a different *kind* of talk, and a different *kind* of relationship:

> line **8**: and you need a bit of time an' but you need *close*ness
> line **9**: you need to work *close*ly with somebody
> lines **11-12**: deeper than just their usual (..) chat (..)
> line **13**: there has to be some kind of closeness
> lines **15-17**: it's like any (.) any two people (..) sharing something (.) you know (.) they have to be on a certain level together

SN 16's repeated use of "close" (*close*ness and *close*ly) again suggests movement.[22] She felt that continuity of care, time, and the trust associated with these were necessary for this movement "closer;"[23] I later had a conversation with her (which wasn't taped) in which she talked about being a part-time worker and expressed her awareness of the importance of continuity of care. SN 16 felt that continuity of care built trust between workers and patients over time, enabling them to move "closer" together, so that patients might ultimately feel able to open discussion on "deep" issues with workers. HCC 11 also commented that particular kinds of relationships between workers and patients were necessary for "getting deeper," and, in her discussion of how these relationships developed, she again used a metaphor of movement (line **2**).

Transcript 5.08

	1	**11**: they [*relationships with palliative care patients*] tend to sort of (.)
->	2	it tends to sort of roll along much quicker than it normally would
	3	if you were meeting somebody at the bus stop or (.)
	4	or going out for a drink or something (..)
	5	it very quickly becomes (..)
	6	you probably **encour**age it cos it's (..)
	7	you prompt people to (..)

[22] See Jan Savage's discussion of the metaphor of "closeness" in nurses' relationships with patients in Savage (1995), *Nursing Intimacy: An Ethnographic Approach to Nurse-Patient Interaction.* London: Scutari Press.

[23] I was also aware of the importance of continuity in my relationships with patients, where continuity was more important than in my relationships with workers, which seemed to persist although our contact occurred only at irregular intervals. However, this irregular contact was common in relationships between nurses, who, due to working shifts, were used to not seeing each other regularly.

-> 8 to *tell* you (.) you you're asking what are you afraid of?
-> 9 and we only *tell* people we trust what we're afraid of (..)

[**me**: mmm

10 I mean you (.)
-> 11 you have **got** to have some kind of relationship before you can say to somebody
-> 12 I'm so scared I'm so (..)
13 you don't start saying to (..)
14 umm (..)
15 just anyone (..)

Note HCC 11's comments on fear (lines **8, 9, 12**), which echoed those of SN 17 (transcript 5.04, lines **98-100**), However, HCC 11 was talking about patients' fear, rather than SN 17's focus on workers' fear (associated with engaging with patients' fear).

Sr 13 was an Irish nun in her mid-40s, who was the deputy matron at St Z's when I began my fieldwork. A few months before I completed my fieldwork she returned to the parent hospice in London (and was replaced as deputy matron by HCC 11). In my interview with her Sr 13 also spoke about a movement in relationship, or in the attitude of the carer:

Transcript 5.09

1 **13**: science and medicine in this (.)
2 part of the century teaches us that (..)
3 there's just *so* much we can **do**
4 *no*thing should be impossible
5 and (..)
6 °there *are* things that are impossible°

[**me**: mmm

7 errm and it's (..)
8 no shame to (.)
9 scientists or anyone else (.)
10 or nurses or doctors umm (..)
11 ((ttt)) I think if (.)
12 probably (.)
13 when people have been working in the hospice for a *while* and (..)
14 a lot of that (.) a lot of that attitude (..)
15 may come from their own personalities
16 err people's (..)

-> 17 you know certain people are more the kind of *do*ing people
-> 18 and they want to **do** things (..)
-> 19 and (..)
-> 20 hospice care I think is very much about (..)
-> 21 ((ttt)) *be*ing (..)
-> 22 when all the doing things are done
-> 23 and you've done everything that you can to make the person comfortable
-> 24 a **lot** of it is about *not* doing
-> 25 it's about **be**ing there and sitting (..)
-> 26 just **be**ing there (..)

In lines **17-18** Sr 13 talks about "doing" people who "want to **do** things," and (lines **21-22**) contrasts this with "*be*ing (..) when all the doing things are done" or "being there" (lines **25-26**). Later on during this interview, Sr 13 and I returned to discuss how workers made this movement from "doing" things to "being there" for patients. Sr 13 commented that, while some "doing" was always necessary, some workers found it difficult when they were unable to do very much (physically) for a patient. She continued:

Transcript 5.10

-> 1 **13**: you could say at the *do*ing stage when (..)
-> 2 symptoms are (..)
-> 3 you're doing your best to keep symptoms under control (.) to (..)
-> 4 physically make somebody feel better
-> 5 when you've done that then you'd better *watch out* because
6 as soon as you've taken *that* away (..)
7 immediately then after that they (.) they want umm (..)
-> 8 the (..) pain the worry the fears all of these errm
-> 9 which is probably the time of *be*ing errm (..)
-> 10 and at that point there isn't any magic pills potions procedures (..)
-> 11 err (.) special beds mattresses drugs that you can employ
-> 12 you can do nothing (.) the only thing you've got at that point in time (..)
-> 13 may well be physical presence but errm (..)
14 **that** is *prob*ably the moment when (..)
-> 15 most of us want to run away and hide
16 because I think there's something within us ((ttt)) err (..)
-> 17 *ve*ry strong within us an instinct that we want to run away from suffering

Thus, for Sr 13, the "doing" stage (addressing patients' physical prŏblems) preceded the "being" stage when workers addressed the non-physical issues which arose for patients. This perception was similar to those of Dr 5 (transcript 5.06) and SN 16 (transcript 5.07) that physical symptoms had to be addressed first, and, again,

resonated with the way in which case conferences in St Z's (as I showed in the previous chapter), focused predominately on physical care.[24]

Sr 13 also talked about fear, and moved from talking about "the (..) pain the worry the fears" of patients (line **8**) (which HCC 11 also discussed, transcript 5.08) to consider *workers'* fears about addressing patients' suffering: "most of us want to run away and hide [...] we want to run away from suffering" (lines **15-17**) (see also SN 17, transcript 5.04). Sr 13's comment (line **5**) that when you've kept symptoms under control and made somebody feel better physically, "then you'd better *watch out*" also suggests this sense that workers experienced a kind of fear or apprehension, perhaps associated with their own vulnerability and uncertainty about what to "do," or how to "be" (or how to "do" "being").

Sr 13's suggestion that workers experienced fear or apprehension in these situations resonates with SN 17's implied suggestion that workers were fearful of addressing "deep" questions from patients (transcript 5.04). In lines **10-13**, Sr 13 suggests that workers had no specific techniques for addressing patients' suffering,[25] only their "physical presence." Her statement that at this point workers wanted to "run away" implies that "just **be**ing there" was not a passive act but involved work on the part of workers, to stay with the patient and resist their desire to "run away."[26] That is, the movement of Sr 13's "run away" is opposed to the movement closer of "just being there."

Earlier in this interview, Sr 13 had commented on *patients'* fears of addressing those questions which, she said, "*they* don't want to face." She had been saying that, given that people's personal spiritual beliefs or life philosophies were particular to each person, the related care also had to be very specific for each person (also see SN 16's comments (transcripts 5.06 and 5.07)). Sr 13 had talked about the importance of listening for "the clue" about what was important to patients, whether praying to a

[24] Also see Sr 13 in the next transcript (5.11, line **6**): "when their physical symptoms are under control."
[25] See my earlier discussion of expertise and the sense of workers that some things were "not my job."
[26] See also my conversation about running away with SN 17, transcript 5.04.

particular saint, reading a particular poem or a particular verse in scripture, and I asked her whether she ever initiated spiritual care. She replied:

Transcript 5.11

	1	**13**: *ve*ry often I think in hospice care
	2	when patients *reach* us they're often (..)
->	3	they often lack the energy for (.)
->	4	too much **in depth** kind of analysis errm (..)
->	5	and it's really only when they're actually *feel*ing ok (.)
->	6	when their physical symptoms are under control and they're feeling ok (.)
	7	that they actually (..)
	8	or even begin to (..)
->	9	*ques*tion or *think* about their predicament (.)
	10	the predicament in which they find themselves
		[**me**: mm mmm
	11	and so (..)
->	12	you have to wait **their time** and sometimes people (..)
->	13	*want* to talk about it and that's when they'll put their toe in the water (..)
->	14	try it and (..)
->	15	because it's bringing up too many other (..)
->	16	questions *they* don't want to face they want to withdraw it very quickly
		[**me**: mmm
	17	and (?I) (..)
->	18	emm.(.) when the need is there they know (..)
->	19	you're there and you'll listen
->	20	and when they're ready they can come back again

Note that Sr 13's talk was much more fluent than that of HCC 11 and SN 17, although similarly full of metaphors of movement, for example: "they'll put their toe in the water" (line **13**), which suggests that patients actively initiate talk about "their predicament" (line **9**), although they are also ambivalent about addressing it: "they want to withdraw it [*their toe*] very quickly" (line **16**).

Sr 13's talk also, again, conveys the sense of spirituality and spiritual care being somewhere other than the day-to-day – "**in depth**" (line **4**) as opposed to surface. Her metaphor of putting a toe in the water also implies depth; something below the surface of the water. Her talk also suggests that (perhaps *because* spirituality and spiritual care are elsewhere?) energy is needed for spiritual talk: lines

3-4: "they [*patients*] often lack the energy for (.) too much **in depth** kind of analysis." That is, Sr 13 perceived that energy or strength was needed for both workers and patients to face patients' spiritual questions, perhaps to deal with the fear associated with them.

lines **12-16**: you have to wait **their time** and sometimes people (..) *want* to talk about it and that's when they'll put their toe in the water (..) try it and (..) because it's bringing up too many other (..) questions *they* don't want to face they want to withdraw it very quickly

lines **18-20**: emm.(.) when the need is there they know (..) you're there and you'll listen and when they're ready they can come back again

In these segments of talk, Sr 13 suggests that patients took an actively initiatory role in opening "deep" discussions, and her remark that "when the need is there they know (..) you're there and you'll listen" raise the question of how patients know that a particular worker is "there and will listen." Unfortunately, during my interview with Sr 13, I did not register nor (therefore) pick up on this comment. However, SW 12 had mentioned something similar when (in an untaped conversation) she talked with me about how she arranged to speak with patients:[27]

SW 12: it's not always easy to talk to the patients, either. You'd think just being round the corner would make it easier, but I'm back and forth between my office and the ward. They might be sleeping, or with their family – and that's their time; don't want to encroach on their time – or here [*tea bar*] having a coffee. And there's also the question of whether they *want* to talk. Always have to put the patient and their family first.

me: and how do you know if they want to talk?

SW 12: it could be a word or a phrase, or looking at their expression; when their expression doesn't match what they're saying. And you ask, but they might not be ready, might go off at a tangent. Something that always sticks with me, when I was a hospital social worker many years ago, a young woman, 32, she was a nurse, in a side ward and her husband had been with her, and he left and she was quite distressed, and I said you're feeling distressed, and she said it's when people talk about the future and you know that there's no future. And I said is that how you feel, there's no future? and she looked straight at me and then changed the subject completely. Because I hadn't given her reassurances: oh no, you

[27] Because this conversation was not taped, the above is not a transcript, but an assembly of comments and remarks by SW 12 which I noted immediately following the conversation.

know things will get better. But she wasn't ready. And you have to be patient, you might look at someone and think you know what they need, you know how to help them, but you have to wait until they're ready.

SW 12's remarks: "they might not be ready," "she wasn't ready," "you have to wait until they're ready" echo Sr 13's comment that: "you have to wait **their time**." That is, both Sr 13 and SW 12 noted that workers had to be ready for when *patients* were ready to discuss issues about death and mortality, and also implied that workers had to *signal* that they were available or ready to have such discussions when or if patients wanted them: "when they're ready they can come back again." Thus, again, "just being there" was not a passive act. "Being there" implied that workers both signalled their availability to discuss spiritual or existential questions with patients, and were also prepared to seize the moment if a patient seemed to indicate that s/he wanted to discuss such questions, that is, that they were ready to pick up the subtle cues which might indicate this. This active attention was more than SN 2's "You just love them, you just do."

In addition, for Sr 13, "being there" included probing for patients' spiritual concerns. As I continued talking with her, I asked her if she could expand upon an earlier (untaped) conversation we had had, when she had told me that she had read that Cicely Saunders would ask patients: "how are you in your spirit?"

Transcript 5.12

->	1	**13**: I think what she was trying to do was actually to get beyond (..)
->	2	the *phy*sical how are you today Mr Smith oh my leg doctor and so on
	3	and her way of of getting the next part of it was how do? (.)
->	4	how are you in your spirit? ((ttt))
	5	which was her way of doing it
	6	I remember when I read it the first time I thought this is really (.)
	7	kind of sounds (.)
	8	quite odd the way err (..)
	9	I thought it was a kind of
	10	a much more kind of *En*glish kind of way of more sort of saying (..)
	11	but as time went by I began to understand more of what she was
	12	actually trying to *get* at
->	13	that she may well have been trying to get at the step beyond the leg
->	14	as it were
->	15	she may well have been trying to get to something deeper than that

[**me**: mmm

-> 16 I think she (.) that was the question she used to try and get beyond the (..)
-> 17 the leg (.)

18 **me**: right because it relates to this, you know, that when (.)
19 when you say to somebody "how are you" they tend to talk about their

[**13**: that's right

20 illness and... [**13**: how do you get beyond?

21 **13**: personally one of the (..)
22 my ways of doing it is (..) err (..)
-> 23 you've *got* to
-> 24 you've **got** to hear the first part of the story (..)
-> 25 you've *got* to hear about the leg (..)
26 you *have* to

[**me**: mmm

27 errm (..)
28 because that's the immediate part of the, the thing that's
29 that's preoccupying them whatever it is

[**me**: mmm

30 errm (..)
-> 31 how are you today Mrs and how's the leg err (..)
-> 32 oh this this and this and what I would say after that is and how are *you*? (...)
-> 33 but because we've gone through the pre*lim*inary part of that (..)
-> 34 it's (..)
-> 35 it's *ob*vious that I'm not *talk*ing about the leg

[**me**: mmm

-> 36 I'm now talking about *you* (..)
-> 37 that seems to me (..)
-> 38 of all the different kind of formulas I've used
-> 39 that seems to kind of get us to *you*

[**me**: mmm

-> 40 how are *you*?

[**me**: mmm

41 err (..)
-> 42 and sometimes you can actually even go (..)
-> 43 be*yond* that again because the *next* stage of that they may well tell you

-> 44 oh I'm feeling a bit worried about this or (..)
-> 45 err it's our Marion or Colin or whatever
-> 46 and after you've gone through **that** level
-> 47 you can *then* go deeper again and say (..)
-> 48 how are **you**? (.....)
-> 49 using a slightly deeper (..)
-> 50 err (..)
-> 51 stronger emphasis (..)
-> 52 you can *then* (..)
-> 53 get maybe more (..)
54 it depends it just all depends on who
55 who you're speaking to

[**me**: mmm

56 whether they have that capacity to kind of hear and (..)
57 understand
58 but some people have
59 their door closed and they just don't want to think of anything more

[**me**: mmm

60 umm (.....)
61 but that's (..)
62 my particular one at the moment
63 and I'm going to use it until I find something else ((half-laugh))

Note, again, Sr 13's use of locational metaphors: "beyond," "deeper," "level," together with metaphors of movement: "gone through," "go" or "get to something" "deeper," and, in particular, "get beyond:"

lines **1-2**: I think what she was trying to do was actually to get beyond (..) the physical

lines **13-17**: she may well have been trying to get at the step beyond the leg as it were, she may well have been trying to get to something deeper than that, I think she (.) that was the question she used to try and get beyond the (..) the leg

lines **46-47**: after you've gone through **that** level you can then go deeper again

lines **52-53**: you can *then* (..) get maybe more

Sr 13 did not only express her sense that spiritual issues were "deep" explicitly (by saying "deeper" and "deeper again"), but also through her intonation, which, as she noted, became increasingly emphatic on the "you" of each "how are you?":

line **31**: how are you today Mrs and how's the leg?

line **32**: how are *you?*

line **36**: I'm now talking about *you*

line **39**: that seems to kind of get us to *you*

lines **47-48**: you can *then* go deeper again and say (..) how are **you**?

lines **49-51**: using a slightly deeper (..) err (..) stronger emphasis

Sr 13's reiteration of "how are you?" in conjunction with her phrases: "get to something deeper" (line **12**) and "get us to *you*" (line **39**) suggest that, for her, the something that was deeper was *you*. Sr 13's repeated use of "how are you?" as a deliberate, pragmatic strategy for moving "deeper" through the "levels" of the person she was speaking to is particularly interesting in comparison to SN 17's comments (transcript **5.04**, line **83**) on how some workers used the phrase "how're you doing?" as a way of *not* engaging with patients' concerns. This latter use of "how're you doing?" is equivalent to the first of Sr 13's sequence of three, in line **28** ("how are you [...] and how's the leg?"), where she explicitly indicates that she is asking about the patient's physical health. By doing so, Sr 13 addresses (pre-empts) the "phatic communion" aspect of "how are you?", that is, the conventional use of "how are you?" as a way of organising the opening phase of an interaction[28] (the way in which the workers SN 17 mentioned used the phrase). Sr 13 deliberately indicates that she is seeking information.

Sr 13's approach was similar (although less explicit) to the plan which Dr 21 told me he had made to begin actively pursuing patients' spiritual concerns. **Dr 21** was a male doctor in his mid-late 30s who was appointed as a second full-time palliative care consultant in St Z's in September 1998.[29] He had previously worked as

[28] Justine Coupland, Nikolas Coupland and Jeffrey D Robinson ((1992), '"How are you?": negotiating phatic communion,' *Language in Society*, 21: 207-30) discuss variable responses to "how are you?" and the negotiated character of phatic responses to the phrase. They show that even in health care situations "how are you?" is often heard as a conversational opener rather than a request for information. Also see Harold Garfinkel (1967), *Studies in Ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.

[29] This was just as I had completed the most involved phase of my fieldwork and was beginning to reduce the number of days I was in St Z's (see chapter three). This was also a point at which half the beds on St E's (hitherto the elderly care ward) had been transferred to palliative care beds, under the care of Dr 21 (while those palliative care beds still in St P's were under Dr 5's care).

a registrar on a hospital palliative care team, and was one of the few people I talked to in St Z's who had planned to work in a hospice (rather than ending up there more or less by accident). He was an Episcopalian Christian with a very strong religious faith. During my interview with Dr 21, I asked him whether he would call any part of his interactions with patients spiritual, and he replied:

Transcript 5.13

	1	there are *times* when I talk to people about what I would (..)
	2	regard as (.) as definitely spiritual things (..) errm (.....)
	3	I suppose (..)
	4	the rest of the time (..)
	5	I (..)
	6	they may be spiritual and I'm just not labelling it as such (..)
->	7	if I'm talking to someone about (..)
->	8	what (..)
->	9	whether they're scared about what will happen after they die
->	10	then that's *clear*ly spiritual (..)
->	11	err if I'm talking to someone about whether they're scared of
->	12	or whether they think they're *dy*ing (..)
		[**me**: mmhm
	13	errm (..)
->	14	I'm trying to get a feel for whether they want to know
->	15	and whether there are (..)
->	16	things that they feel they need to re*solve* an' umm (.)
->	17	I wouldn't necessarily label that as spiritual but other people might (..)
		[**me**: mmhm mmhm
	18	it doesn't umm but (..)
	19	but then that just becomes a *la*belling thing (.)
->	20	if I'm talking about umm whether there's
->	21	what they think about will happen after their (.) after their dying
->	22	an' whether that's frightening for them errm (..)
->	23	and whether they have a faith an' whether their faith
->	24	their faith helps them *in* that errm (..)
->	25	then there's a there's a *clear*ly (.) I would I would (..)
->	26	say those are the times when you're talking about spiritual things (..)

Like Sr 13, Dr 21 was unusual amongst my interviewees for his ability to clearly identify the issues which he felt were distinctly spiritual (lines **7-12**, **14-17**, **20-26**). He had earlier told me that what he perceived himself as doing in his practice was

responding to people's expression of their needs. I asked him whether he only responded to people or whether he ever initiated discussion of people's spiritual needs, and he said that recently (following discussions with a friend of his (a GP who had done a theology degree after qualifying) about the role of his faith in his practice as a palliative care doctor), he had begun to think that he should specifically do this:

Transcript 5.14

	1	**21**: I've been thinking
	2	that it is reasonable and right to be asking people (..)
	3	umm about (..)
	4	their beliefs (..)
	5	because I ask people about their families and I ask people about (..)
	6	their fears and whether (..)
	7	err and I try to respond to *those* things (..)
	8	and so actually it's a natural (..)
->	9	and and it's only if you give people the oppor*tu*nity
->	10	if you use those words (..)
->	11	you know if people talk to me about what happened in hospital and (..)
->	12	unless I say something like "how did you *feel* about that?"
->	13	then they don't tell me how they feel (..)
->	14	and so (.) so they don't tell me about their e*mo*tions unless I in*vite* them to (.)
		[**me**: mmhm
->	15	and so I think it *may* be true also of (..)
->	16	errm (..)
->	17	their (..)
->	18	beliefs or their err (.....)
->	19	their (..)
->	20	spiritual needs (.)
->	21	that they're not going to *talk* about it even though it would be helpful
->	22	they're not going to talk about it unless I (..)
->	23	give them the opportunity to (.)
	24	rather than just (.)
	25	you know saying "anything else you want to (.) to talk about?"
	26	in a very *o*pen way
->	27	in a more err (.) in a more di*rec*ted way (.)
->	28	give them the opportunity to speak about these things
		[**me**: mmhm
	29	so I'm just starting out on that umm (..)
->	30	"wee experiment" in these last few weeks

Thus Dr 21 talked about deliberately probing for patients' spiritual concerns (lines **9-23**), similarly to Sr 13's talk about intentionally moving through the levels. Dr 21 drew a parallel between this and his active eliciting of their emotional needs (lines **11-14**), framing this in the voice of science and professional reflexivity, although undercut slightly by modifying it with "wee": "wee experiment" (line **30**). As discussed, it was only Dr 21 and Sr 13 who had such a considered approach to the spiritual aspects of care, and they were in a minority of the minority of workers who identified any such aspects to care at all.

DISCUSSION AND CONCLUSION

In general, therefore, although most workers in St Z's distinguished between religious and spiritual care, saying that spiritual care was not religious care, they found it difficult to say anything more than this. Many workers collapsed spiritual care together with emotional care, and/or said that they personally did not provide it. One of those few workers who did identify specifically spiritual aspects to their and/or others' care located these in her *attitude* towards the people she cared for: "you just love them, you just do." This generally caring attitude might be thought of as coming from this person's spirit, such that spiritual care meant that all her actions were loving, and motivated by love, rather than as anything to do with the *content* of the care which she provided.[30]

Others of those few workers who said that spiritual care existed identified it in terms which implied, or explicitly stated, that it was something more than an attitude. These few workers often spoke of "spirituality" or "the spiritual" using metaphors of depth and/or distance, locating them "deep," "beneath" or "beyond." For them, spiritual care meant "going deeper" or "getting beyond," that is, particular *actions*.[31]

[30] In contrast, when I asked workers similar questions about physical, social, or even emotional care, their answers usually referred to actions of some kind.

[31] In parallel, religious care also involves action – religious practices, such as Mass, blessings, confession, sacraments – as well as a loving attitude.

In her discussion of the relationship between care and ethics, Peta Bowden[32] cites Patricia Benner and Judith Wrubel's argument that emotional connections are central to people's involvement in situations, giving access to the kind of global understanding that is, they claim, central to expert nursing care. Benner and Wrubel state that "expert nurses" blend rational, instrumental approaches with emotional expression, and that such nurses thus implicitly challenge the distinction between "taking care of" and "caring for and about," that is, between "instrumental" and "expressive" roles. Benner and Wrubel argue that the distinction between these roles is a conceptual one, which, if nurses carry it out in practice, does "violence to caring."[33]

However, this distinction is not only conceptual, since it does happen in practice (if not, Benner and Wrubel would not perceive the need to argue against it). Benner and Wrubel are thus prescriptive rather than descriptive, or describing (only) a particular group of nurses, whom they define as "expert" (thus, by definition, this group does not include all nurses, let alone all health care professionals). I don't think that nurses – and other health care professionals – always deliver the interwoven instrumental and expressive care for which Benner and Wrubel argue, but each type of care can occur separately, such that expressive care may occur in the absence of instrumental care, and vice versa.

An example of expressive care without instrumental care could be when a nurse facilitates someone's caring for themselves, such as actively refraining from doing someone's cardigan buttons up for them. That is, the nurse refrains – as an active choice, not a passive act – from performing an instrumental, "taking care of,"

[32] Bowden, op. cit., note 6.

[33] Benner and Wrubel, op. cit., note 4: 170. The distinction between instrumental and expressive is sometimes equated with that between cure and care (the former being associated with allopathic medical doctors and the latter with nurses). As nursing has become increasingly professionalised (as for example with *Project 2000*), there has been an increasing concern in nursing with what is often perceived to be an associated increased focus on the technical, often understood as instrumental care. See for example Celia Davies' discussion of what she calls the "Polo mint problem," and her argument that the professionalisation of nursing has led to a situation whereby non-technical nursing, which she considers the most important element of nursing, "drops through the middle." (Davies (1995), *Gender and the Professional Predicament in Nursing*. Buckingham and Bristol, PA: Open University Press). However, I suggest that spiritual aspects of care understood as care which has a particular content implies a kind of non-technical instrumental care.

action. Conversely, instrumental care may be performed with little or no expressive care, for example, bathing someone in a brusque or offhand manner. Yet, while the latter type of action may leave a person's emotional needs unmet, or indeed even create such needs, their physical needs have still been met; they have been bathed. Benner and Wrubel might argue that such behaviour is not care/caring, but this then becomes the semantic question of what to call actions which meet people's physical needs, but do so in an offhand manner. (Or, on the other hand, expressive "care" which does not address people's physical needs).

I suggest that the distinction which I have made between an attitude towards the person being cared for, or the *manner* of care, and an action, or the *content* of care, could be equated with Benner and Wrubel's distinction between *expressive* and *instrumental* care. Workers' active avoidance of "deeper" questions, which SN 17 commented upon, might be considered to be neither expressively nor instrumentally spiritual care. The spiritual aspects of care which one worker in St Z's said was present in her attitude or manner towards patients could be considered "expressive." Expressive spiritual care, with no instrumental dimension, might then mean that a carer provides "TLC" without actively engaging with the spiritual questions of the person they are caring for. "Instrumental" spiritual care would then be the sense in which some workers in St Z's understood spiritual care: as a particular action: "going deeper" with a patient.

It seems to me that a distinction between "expressive" and "instrumental" spiritual care is implicit in much of the literature addressing spirituality in health care.[34] Much discussion of spiritual care equates it (explicitly or implicitly) with the attitude of the carer (that is, what I have defined as the manner, or the expressive component, of care). So, for example, Verna Carson states that spiritual care refers to the offering of self; "the attitude of agape or brotherly love that is inherent in the Judeo-Christian ethic."[35] That is, for Carson spiritual care is primarily expressive,

[34] This literature has grown significantly in recent years, as Wilfred McSherry and Linda Ross note (McSherry and Ross (2002), 'Dilemmas of spiritual assessment: considerations for nursing practice,' *Journal of Advanced Nursing*, 38(5): 479-88).

[35] Verna B Carson (1989), 'Spirituality and the nursing process,' pp. 150-79 in Carson, VB (ed.) *Spiritual Dimensions of Nursing Practice.* Philadelphia and London: WB Saunders: 163.

although she does state that important elements of this include a nurse empathising, being available, vulnerable and committed,[36] which are perhaps more than attitude alone.

Other writers argue that a loving attitude alone on the part of the carer does not necessarily equate with spiritual care.[37] "TLC" may express the carer's spirituality and love or concern for the patient, and may meet (whether completely or in part) a person's need to feel loved, but TLC alone does not mean that the "TLC-er" engages with a person's spiritual concerns, or accompanies that person in exploring their "Why me?" questions. Nevertheless, "expressive" spiritual care, associated with continuity of care, builds trust and facilitates the development of intimate relationships between people (as SN 16 and HCC 11 commented), and, therefore, may be a necessary condition for "instrumental" spiritual care.

A few workers in St Z's did consider that spiritual care was *instrumental*, having a particular *content*. It involved "going deeper," and to them this meant actively engaging with patients' spiritual concerns, questions and/or distress; taking care of (all of) the spiritual needs of the cared-for person.[38] Similarly, Linda Ross argues that "being with" is an action, an active state, which is more than (only) passive love from the carer.[39] She states that nurses can give spiritual care on different levels – from "deep" (note, again, the metaphor of DEEP) to "superficial" – and defines the "deep" form as being "intimately involved in helping patients meet their spiritual needs," which she equates with "being prepared to 'be with' the patient."[40]

---

[36] Carson, op. cit., note 37: 164. Note Carson's point that spiritual care involves vulnerability (as I touched on earlier), and also that if spiritual care is solely expressive (a loving attitude) it is possible that people can give this kind of care unknowingly.

[37] For example, Linda Ross (1998), 'The nurse's role in spiritual care,' pp. 119-35 in Cobb, M and Robshaw, V (eds.), *The Spiritual Challenge of Health Care*. Edinburgh and London: Churchill Livingstone. Also see Linda Ross (1994), 'Spiritual aspects of nursing,' *Journal of Advanced Nursing*, 19: 439-47.

[38] I never heard this kind of active engagement from workers, but, as I discussed in the previous chapter, I was aware that such conversations occasionally happened between workers and patients in private, since both workers and patients talked about them. (The fact that such conversations were themselves topics of conversation, however, suggests that people perceived them as unusual, as with the conversation between SN 25 and Maggie C which I discussed in the previous chapter).

[39] Ross (1998), op. cit., note 39: 131.

[40] Ross (1998), op. cit., note 39: 127.

St Z's workers also used a DEEP metaphor when they spoke about spirituality. As Lakoff and Johnson argue,[41] we all (unavoidably) use metaphors, particularly physical metaphors, when discussing less concrete concepts – I have done so throughout this chapter (as throughout the rest of my thesis) – so workers' use of metaphor *per se* was not significant. However, the *particular* metaphors which they used were significant because, as Lakoff and Johnson argue, metaphors have a shaping or framing function.

Thus, as I discussed in the previous chapter, when workers were talking about people who they perceived as more likely to die, they used the metaphors of "going down" or "going downhill," which had strongly negative connotations through their association with the metaphoric pair UP-DOWN. Sr 13 was aware of the significance of the particular language which workers used to talk about issues relating to patients. When she was talking with me about her sense that many workers in hospice had to deal with feeling that they had failed when someone was dying, she commented:

Transcript 5.23

	1	**13**: I mean personally (..)
	2	it's something *I've* probably focused on in myself because I found there (..)
->	3	I found that sense of failure when somebody (..)
->	4	the illness was taking control an' it was winning
	5	and our best efforts in medicine (..)
	6	in a more general sort of (..)
		[**me**: mmm
	7	in a hospital situation wasn't (..)
->	8	°wasn't winning°
	9	but in *hos*pice care we *take* all of that *with* us (..)
	10	ermm and I think on (.)
	11	it's probably something I'm not fully aware of err
->	12	but I do *hear* it hear it in hear it in myself sometimes (.) colleagues errm
->	13	there is a sense that (..)
->	14	a sense of guilt (..)
		[**me**: mmm
	15	(ttt) and (..)
	16	I became aware of it in particular funnily enough about a year ago (..)

[41] Lakoff and Johnson, op. cit., note 2.

	17	errm (..)
	18	in my position my position in the hospice errm I spend a lot of time (..)
	19	errm as it were co-ordinating and liasing with nurses and taking the kind of
	20	what you call sort of the report in terms of errm (..)
	21	nurses reporting to me how various patients' conditions are (..)
	22	and listening to how (.)
	23	how different people how different nurses des*cribed* the condition (..)
	24	of patients and *from* that I came across an attitude that errm
	25	I think in a certain sense it's a sense of (..)
->	26	(ttt) oh he's (..)
->	27	errm he's much worse (..)
	28	errm or errm (..)
->	29	things are changing and he's umm he's deteriorating
->	30	but the attitude that was coming across was is umm (..)
->	31	it's getting out of control (..)
->	32	we're *lo*sing and (..)
->	33	about that time I suppose errm I started sort of saying to
->	34	saying kind of more openly to (..)
->	35	colleagues errm oh (..)
->	36	Charlie's getting weaker isn't he?
	37	which is more (..)
	38	trying to get across (..)
	39	this illness is (..)
	40	unfortunately something we can't (..)
	41	we can't actually stop we can do an awful lot better (.)
	42	we can do a lot to make him *feel* better err to make it easier (.)
	43	to give him as much quality of life (.) as much (..)
	44	*liv*ing as *pos*sible
	45	we can't actually *stop* it (..)
	46	to try an' an' (.....)
	47	°maybe° (..)
	48	°getting people to° (..)
	49	°let *go* of themselves (.) of (.) of failure°
	50	°and realise that (.) this is something that is in*ev*itable°

I never heard anyone say that a patient was "getting weaker" (line **36**). I most often heard workers saying that someone was "going down" or "going downhill," and, as I argued in the previous chapter, these metaphors, similarly to Sr 13's comment about "deteriorating," (line **29**) conveyed a strongly negative sense about people's approach to death, associated with the negative connotations of DOWN.

For me, this resonated with workers' use of DEPTH for spiritual issues. Lakoff and Johnson consider the metaphoric use of DEPTH in their outline of the complex coherence between three different metaphors used for discussions or arguments:

BUILDING, JOURNEY and CONTAINER.[42] These three metaphors are not consistent with each other, in the sense of being identical, but there is a coherence between them, since they do not contradict each other, but relate to different aspects of the concept for which they are being used.[43] Lakoff and Johnson point out that DEPTH is often used for discussions or arguments, and that it is defined relative to a surface. For the BUILDING metaphor, the depth-defining surface is ground level, whereas for the CONTAINER metaphor it is the surface of the container. In the BUILDING and CONTAINER metaphors, what is deeper is more basic: the "foundation" and the "core" of the argument, and "deep" facts are also those that are not obvious. In addition, all these ARGUMENT metaphors overlap with the MORE IS BETTER metaphor, and this results in another cross-metaphorical coherence, such that the quality of an argument can be assessed in terms of quantity: whether it has *enough* depth, that is, *sufficient* detail.

Lakoff and Johnson argue that the JOURNEY metaphor for an argument also coheres with the UNDERSTANDING IS SEEING metaphor: when you travel you see more as you go along; as you go through the argument you see more, so you understand more. So, too, the metaphor of "going deeply" into a subject indicates that the superficial points in an argument, those which are "on the surface," are easy to see (and understand), while those which are deeper are not easily seen. Lakoff and Johnson say that "It requires effort – digging – to reveal them [*the deeper aspects of the argument*] so that we can see them."[44]

Thus, Lakoff and Johnson claim that what may at first appear to be random, isolated metaphorical expressions, which we take for granted, turn out to be not random but part of whole metaphorical systems which serve to characterise a concept in all its aspects. They do not provide a single consistent image, but they are coherent, and fit together where they overlap.[45]

---

[42] Lakoff and Johnson, op. cit., note 2: 100-5.
[43] Other coherences relate to the content-defining surfaces of some of these metaphors; as an argument proceeds, it acquires more content and more of a surface is created.
[44] Lakoff and Johnson, op. cit., note 2: 103. Note that "digging" is itself a metaphor, and also note their use of UNDERSTANDING IS SEEING metaphors: we "reveal" or "see" deeper aspects of an argument.
[45] Lakoff and Johnson, op. cit., note 2: 105.

Lakoff and Johnson's analysis of the BUILDING, JOURNEY and CONTAINER metaphors for arguments, and the importance of DEPTH, links with St Z's workers' concept of spirituality. As I have discussed, those St Z's workers who had such a concept defined it as something which was "deeper," "beneath" or "beyond," while Dr 5 defined it more particularly as "under the ego" or "what you're left with when all worldly things are stripped away." In relation to the JOURNEY metaphor for this concept, the depth-defining surface is "here," the quotidian; for the BUILDING and CONTAINER metaphors it is the surface or the outside of a person.

The JOURNEY metaphor for spirituality also overlaps with UNDERSTANDING IS SEEING: as you go more deeply into someone's spirituality, you see and understand more; the superficial aspects, on the surface of a person, are easy to see; those which are deeper are not easily seen,[46] and need to be "dug for," which requires effort. For St Z's workers, approaching a patient's spirituality involved "getting" or "going" beneath, or even "removing," the "layers" of the patient (which Dr 5 described as ego on the surface, emotion beneath, and the spiritual self beneath that). That is, workers needed to "dig for" (elicit) a person's spiritual needs, and this implied action and effort on their part.

"Getting deeper" with a person also implies emotion, vulnerability and loss of control, which both you and they experience if you accompany them "deeper;" that is, as part of the "digging" the "digger" needs to face their own mortality and associated fear and uncertainty. This implies the need for emotional and spiritual strength and courage (at least initially, when this is an uncertain area and unusual experience for the "digger"). For workers in St Z's "here" was normality, and (as with DOWN) to go "there" – in this case, DEEP – required movement, which required effort. I suggest, therefore, that if workers located spirituality and spiritual issues DEEP, they were perhaps more likely to give emotional care, since this was easier to provide, requiring carers to go less "deep," and therefore demanded less effort from them. Perhaps, also, not going deep was less threatening to workers, since they

[46] Also see SN 16's comment that Jimmy M was a "deep" (in the sense of thoughtful) person, which I referred to in the previous chapter.

would have more control and be less vulnerable if they "kept things" at the "level" of their "usual chat."

It could be argued that spiritual care is so profoundly a "being" activity that it is artificial to try to talk about it, since it (necessarily) cannot be talked about but only experienced; hence my interviewees' struggles with definitions. However, a few St Z's workers, notably Dr 21 and Sr 13, *were* able to talk about "doing the being," and it seemed to me that these more articulate workers were those who had a more instrumental attitude to spiritual care. They were also people who were overtly religious. Both Sr 13 and Dr 21 had a strong faith (although, interestingly, and perhaps challenging stereotypes of nuns,[47] despite the fact that Sr 13 was a nun, she was more open to accept people's different and various concepts of God than was Dr 21).

Prior to the arrival of PCC 24 at St Z's, just before I completed my fieldwork,[48] Sr 13 and Dr 21 were the only two of my interviewees who discussed an active strategy for spiritual care with me. Both explicitly talked about probing for patients' "deep" issues (although Sr 13, in her role as deputy matron, seldom did "hands-on" nursing, and had relatively few interactions with patients, in those she did have she actively pursued their spiritual concerns). This active eliciting of patients' spiritual needs suggests that there is an additional distinction within Sr 13's distinction between "doing" and "being there," such that "being there" can be passive or active, the latter meaning that the carer is ready to "do," that is, sensitive and ready to respond to patients' cues that they wish to discuss spiritual issues, or even initiating such discussion.

Both Sr 13 and Dr 21 had a high status within the hospice, and were, associated with this, more autonomous, being accountable to fewer people than were

[47] Prior to my fieldwork I had never met any nuns, yet I had ideas about what nuns were like, as became evident to me when Sr 8 and Sr 13 were not as I expected (though I cannot say exactly what I did expect).

[48] Incidentally, PCC 24's perspective on spiritual care was that it encompassed emotional and psychological care. He argued that if spiritual care is given, the other needs will be met. This was the inverse of the perception of some nurses that emotional care (TLC) subsumed spiritual care. I have not discussed PCC 24's perspective in this thesis, since I only have his talk about what he believed and what he planned to do; he was not working there while I was doing my fieldwork.

most workers in St Z's. Their roles were also associated with more practices which were understood to be "instrumental" (that is, actions) than those of many other workers. Thus, perhaps, metaphorically, people who were "high" up felt more able to "go deep" than people who were "low" down.

Most other workers did not feel that they had the skills nor the authority to initiate what might be called "instrumental" spiritual care. Spiritual care was not part of any worker's training, nor of workers' job descriptions, and there was no specific structure for its provision (in contrast to emotional and psychological care). As I have noted, role boundaries and the division of labour between the workers were strong features of St Z's, and with them was associated a pronounced hierarchy between workers and a sense of differential expertise between workers, so some workers were hesitant to act autonomously. For workers to give (instrumental) spiritual care perhaps implied a degree of autonomy which workers generally did not feel that they had.

The broader social context (Britain) within which St Z's was situated, where people in general seldom mention or discuss religion or spirituality,[49] was compounded in St Z's by the particular religious issues which are present in the West of Scotland, and again by its particular situation, as a Catholic hospice in a Protestant town. Perhaps because of these factors, workers in St Z's (for example, SN 2) were reticent about their own religious or spiritual beliefs, and they did not openly discuss spiritual/religious issues. I never heard workers (including those who defined themselves to me as spiritual and/or religious people), other than the nuns and other religious professionals, referring to spirituality outwith interviews or other one-to-one situations, and this contrasted with the relatively open discussion of emotional or psychological issues, such as occurred in the case conferences.

People in St Z's could express and explore publicly recognised forms of spirituality, that is, within a religious framework: there was a daily mass and a weekly ecumenical service in the hospice, and some patients had icons and holy

[49] I suggest that the frequency and public visibility of debates and discussions around death, religion and spirituality in the media are not reflected in day-to-day discussions between people.

pictures by their beds (alongside family photos, get well cards and so on). Other forms of spirituality were not public, nor shared amongst workers (or amongst patients). Workers developed their spiritual understandings (if any) outside St Z's and chose not to share them within. That is, a form of explicitly *religious* spirituality existed, and was constructed, within St Z's, and this co-existed with other forms of spirituality which were kept quiet, privatised, and were apparently individual, although actually shaped in *other* social contexts. Religious professionals might include spiritual care as part of their religious care-giving (that is, for those patients who expressed religious concerns, since, while priests and ministers were available to patients who asked for them, they did not approach patients otherwise (again, perhaps in part because of the religious issues in the West of Scotland)).

I have argued that the instrumental dimension of the spiritual aspects of care involves carers explicitly addressing the spiritual issues, such as "Why me?" questions, raised by the person being cared for, or may even involve carers raising such issues themselves. The risk in this, particularly in the latter, is that the delicate balance between talking overtly about spiritual beliefs and imposing one's own beliefs on other people may be upset. Thus, Dr 21 felt that there was a tension between, on the one hand, being open with patients and, on the other, withholding his own beliefs. Again, this issue, while not unique to St Z's, and perhaps in part being associated with NHS directives not to proselytise, might have been particularly heightened in St Z's in association with the religious tensions in the West of Scotland and/or the particular history of tension when St Z's was first established. This tension would be particularly marked for people such as Dr 21 who had strong beliefs, particularly if they identified as evangelical, and therefore felt that their beliefs were right, and that they needed to share them with others.

I also want to highlight that within the general context of (workers') silence about death and spirituality within St Z's, patients could be seen as providing other patients, and workers, with opportunities to discuss these things. That is, patients could (also) be thought of as "spiritual carers," as being actively part of spiritual care. Arguably, as the movement is "deeper," both into the person and also further away from physical care, the demarcation between the carer and the person they are caring

for becomes increasingly less clear. The uncertainty and mystery of both death and spirituality are such that there are no experts, and this perhaps contributed to workers' difficulty with identifying and/or providing spiritual care, since it runs counter to the emphasis on expertise and "being qualified" within allopathic medical organisations which I have discussed. St Z's workers often talked of their sense of privilege and humility at being so close to dying people at a very intimate, personal time in those people's lives (a sense which I shared).

As I have shown, my conclusions developed from a combination of observation, interviews and participation – the latter of which gave me additional, personal, experiential insight into several things. First, the importance of time, attention, and "TLC" as expressive spiritual care, and as necessary conditions for instrumental spiritual care. Second, the importance of continuity of care as (also) contributing to the building of relationships. Third, the subtle cues by which patients tested carers' receptivity to discussing existential or spiritual issues, and, fourth, the need for carers to be ready and alert to seize the moment when patients sought to open such discussions.

During my fieldwork, it seemed to me that the spiritual aspects of care in St Z's were separated from other aspects of care. Most workers did not feel that this care was part of what they did or were expected to do. One worker said that she provided spiritual care in an expressive sense, and a few other workers talked of instrumental spiritual care, but as an additional activity which people did on personal impulse. So, in relation to the spiritual aspects of care, St Z's was not a thought collective in Fleck's sense; there was no single "St Z's" view on spiritual care, but individualised perceptions and understandings.

So, despite Dr 5's (quite genuine) remark that he felt that spirituality and/or spiritual care were the most important things for palliative care patients, the spiritual aspects of care were not always present in St Z's, and, if they occurred at all, came last "after everything else has been cleared away." As I illustrated in the previous chapter, patients' physical needs/care came first. Although "TLC" met some of patients' emotional and perhaps some of their spiritual needs, the actions of St Z's

workers inverted and contradicted the aim/claim that the spiritual aspects of care were prioritised.

I, of course, developed my own views on spiritual care through my work on this study. For me, while emotional and spiritual care may seem similar on an expressive level – where carers acknowledge people's pain/suffering, and respond to it with TLC (hence some workers' equating of these two aspects of care) – the distinction between them lies in their instrumental dimension, that is, in whether carers respond to the pain and suffering which patients express by identifying and explicitly engaging with people's emotional, spiritual and/or existential concerns and questions. Some patients might need only emotional care (although note HCC 11's claim that people have spiritual needs even if they say that they do not), while others might receive sufficient spiritual (and emotional) support from non-professional carers.[50] However, this cannot be the case for all patients, and, even if it is only a small number of patients who need more than emotional care from professional carers, what happens to them if they don't get that care? Since the spiritual aspects of care did not exist in any systematic way in St Z's, it is very likely that the spiritual or existential concerns of at least some patients who would have wanted this were not addressed.

[50] The philosophy of hospice and/or palliative care, and the move to "holistic" medicine more generally could imply an empire-building move, associated with the issue of the perceived creeping medicalisation of "everything" (Ivan Illich (1995), *The Limits to Medicine: Medical Nemesis: The Expropriation of Health*. London: Boyars) which I mentioned in the previous chapter (also see Carl May (1992), 'Individual care? Power and subjectivity in therapeutic relationships,' *Sociology*, 26 (4): 589-602), but this did not seem to me what was happening in St Z's.

- 6 -

DISCUSSION AND CONCLUSION

INTRODUCTION

My study is an exploration of the relation between theory and practice in two respects: for the people in the hospice which I studied, and also for myself. This dual focus was due to my starting point: the theory that knowledge is socially/culturally constructed; in particular, the position on this which I have called "engaged social constructivism," which explicitly applies social constructivism to all knowledge production, not only that of the people whom the theorist studies, but also that of the theorist her/himself. That is, this position holds that the social constructivist understanding of how knowledge is produced has implications for the practice (production of knowledge) of the theorist of knowledge (knowledge producer) her/himself.

Thus, as the main focus of my study I was interested in exploring how Cicely Saunders' philosophy of "total pain" and "total care"[1] (which, for convenience, I contract to total pain/care) related to hospice practice, and, in particular, to the practices of workers in a specific hospice: "St Z's." I was especially interested in the spiritual aspects of the theory of total pain/care and I therefore particularly sought to explore the spiritual aspects of caring practices in St Z's as part of the "whole" of holistic or total care. In parallel to this, I also sought to explore the relation between theory and practice for myself; that is, regarding my own work on this study.

In this chapter I will discuss the key issues relating to these areas of interest which arise from the findings which I have presented in the previous chapters. I will begin by recapping my research questions and the interests in social constructivist studies of science, technology and medicine (STM) which framed these. I will then move on to reiterate the key points from my findings: the distinction between spaces in St Z's, the associated importance which people in St Z's attached to patients' physical location and movement within and between those spaces, and, linking to

[1] Cicely M Saunders (1984), 'The philosophy of terminal care,' pp. 232-41 in Saunders, CM (ed.), *The Management of Terminal Malignant Disease,* 2nd edition. London: Edward Arnold.

these, workers' metaphorical understandings of death, dying and spirituality; the division of labour between members of the multidisciplinary team; and the fragmentation of care related to these.

Next, I will discuss the relationship between these findings and the understandings which I have drawn from social constructivist studies of STM. In particular, I will consider Kuhn's "disciplinary matrix,"[2] and the implications of this for the relationships between beliefs, theories, knowledges and practices, highlighting metaphysical models (one component of the disciplinary matrix) and relating these to how workers in St Z's understood the theory of total pain/care and its relationship to their practices.

While reflecting on my findings, I increasingly realised that there was a gap between theory and practice, or between "espoused" theories and "theories-in-use,"[3] not only for workers in St Z's but also for myself. This led to my exploration of a range of theoretical positions on the social construction of knowledge, not only the engaged social constructivist position with which I began my research. In my discussion of my investigation of these different positions in chapter two, I aimed to emphasise the process of producing my own knowledge (this thesis), rather than retrospectively "cleaning up" the process I went through, and giving the impression that I followed a single path from beginning to end. In relation to this, I will reflect on my research practice, considering my research methodology and how theory/knowledge relates to research practice.

I will conclude the chapter by considering the relation between theory and practice for theories such as social constructivism and total pain/care, which challenge all the elements of the disciplinary matrix of a thought collective, and reflecting on how people have responded to each of these two theories.

[2] Thomas S Kuhn (1969, 2nd edition), *The Structure of Scientific Revolutions*. Chicago: University of Chicago Press.
[3] Chris Argyris and Donald Schön (1974), *Theory in Practice*. San Francisco: Jossey-Bass.

RESEARCH QUESTION/S AND THEORY

I began this study with an intellectual interest – stemming from my experiences with studying allopathic medicine and, later, IT – in the theory of the social construction of knowledge, and its implications for practice. The work of Thomas Kuhn[4] and Ludwik Fleck,[5] and of later theorists of knowledge who have extended and developed their work, shows that people's scientific beliefs occur within and in interaction with a framework of conventions. These conventions are both local (belonging to people's immediate, physical, community) and wider (belonging to the disciplinary community, or "thought collective," within which they are professionally located). The conventions associated with the wider disciplinary community reflect and are reflected in people's professional practices and their beliefs about which practices are appropriate for them in their particular professional role. Thus, people express wider conventions locally.

That is, social constructivism holds that the context within which people think and act (which includes their professional training and experience) shapes and is shaped by how they think and act, including the kinds of questions they ask, the kinds of information which they deem relevant or irrelevant for answering their questions, and the kinds of answers and actions which they (therefore) find acceptable. Much of the work in this field focuses on natural scientists, but similar issues arise for other users and producers of systematic knowledge, including health care professionals and social scientists.[6]

I was especially interested in the interpretations of this theory, and the associated critiques of scientific knowledge, made by feminists and people from other non-dominant groups – a group of theorists who I refer to as "engaged social constructivists." In brief, these theorists argue for an explicit programme of change.

---

[4] Kuhn, op. cit., note 2.

[5] Fleck, Ludwik (1935/79; edited by Trenn, TJ and RK Merton; translated by Bradley, F and TJ Trenn), *Genesis and Development of a Scientific Fact*. Chicago and London: University of Chicago Press.

[6] See, for example, Deborah Gordon (1988), 'Tenacious assumptions in western medicine,' pp. 19-56 in Lock, M and D Gordon (eds.), *Biomedicine Examined*. Dordrecht, Boston and London: Kluwer, and Deborah Lupton (1994), *Medicine as Culture: Illness, Disease and the Body in Western Societies*. London, Thousand Oaks, New Delhi: Sage.

They claim that, since knowledge is contingent upon its context of production, and a dominant minority of people currently produce knowledge, the production of what is defined as valid knowledge is inherently political, especially in relation to those issues which dominant groups exclude from definitions of knowledge. Engaged social constructivists aim to redress this, in part by redefining knowledge, so that excluded dimensions, such as subjectivity and emotion, are explicitly included and accounted for, as are excluded perspectives. It is this step which distinguishes them from other social constructivists.

At the same time as I began to explore these theoretical positions I had begun volunteering at a hospice in Edinburgh, following the death of a family friend who received hospice home care at the end of his life. As a result, I started reflecting on my mother's life with MS. These experiences led to my interest in hospice/palliative care as a philosophy of care, and, in turn, to my development of a proposal to study workers' practices in a particular hospice, and the links between these and the philosophy of the modern hospice movement.

I was particularly interested in Cicely Saunders' argument that people who were dying needed "total care" in response to their "total pain," and the claim, flowing from this, that workers in hospices and/or palliative care address patients' physical, social, psychological, emotional and spiritual needs. It seems to me that the distinctive feature of hospice and/or palliative care is the claim to provide care which addresses all these aspects of patients' needs; in particular, the spiritual aspect. Since allopathic medicine (like natural science, and (because it is) modelled along the lines of natural science) was specifically constructed to exclude, and by excluding, a spiritual dimension, I perceive Saunders' theory of total pain/care as a radical challenge to allopathic medicine. This challenge is not only theoretical, since Saunders had an explicit agenda to change existing knowledge, and associated practices, in allopathic medicine. She set out to achieve this change by establishing

an alternative model, rather than by working from within existing structures, stating: "We moved out so the knowledge could move back in."[7]

I perceive a parallel between Saunders' aim (changing existing practices in accordance with a new theory that includes issues which the mainstream excludes) and the approach to knowledge of engaged social constructivists. It therefore seems to me that there is a kind of symmetry in applying the latter to the former, and so exploring both simultaneously. I therefore developed a research project to explore care in a particular hospice from an engaged social constructivist perspective, focusing specifically on the spiritual aspects of care.

It might seem contradictory to separate the spiritual aspects of "total care" from the other aspects of care, since this theory claims that all aspects of care are inextricably linked. However, precisely by identifying four or five dimensions or aspects of pain/care (physical, social, psychological and/or emotional, and spiritual), the theory of total pain/care does on some level distinguish between these various dimensions.[8] That is, for this theory these dimensions are distinct, although, importantly, they are not separate. Further, I was not seeking to *separate* the various aspects of care in St Z's but rather to focus particularly on the spiritual aspects.

In this study, therefore, I set out to explore the practices of workers in St Z's, and also to explore their beliefs and understandings (if any) of spirituality and the spiritual aspects of care. I aimed to investigate the relationship between their practices, beliefs and knowledges, and between these and the theory of total pain/care. Since I was interested in workers' practices and the relationship between these and their beliefs and knowledges, I chose to use an ethnographic research methodology. In particular, and in relation to the gap between rhetoric and reality, that is, the difference between what people say (they do) and what they do,[9] I wanted to explore both what workers did and also what they said they did.

---

[7] Cicely Saunders (1981), 'The founding philosophy,' p. 4 in Saunders, C, Summers, DH and N Teller (eds.), *Hospice: The Living Idea.* London: Edward Arnold.

[8] In relation to my study, I would especially highlight the distinction between psychological, emotional and spiritual aspects of pain/care.

[9] Irwin Deutscher (1973), *What We Say/What We Do: Sentiments and Acts.* Glenview, IL: Scott Foresman.

On a more general level, I also sought to reflect upon the implications of adding spirituality to scientific knowledge,[10] given that the latter is constructed to exclude, and by excluding, the former. The modern hospice movement is often characterised as reformist, but it is also increasingly remarked that it has lost its radical edge, and become diluted through "routinisation."[11] The question for hospice is whether a radical movement inevitably becomes co-opted through participation in the mainstream. Similar issues arise for feminist theorists; thus, see the debate concerning whether the invisibility of women can only be remedied by creating entirely new structures, or whether it can be resolved simply by adding women's perspectives to existing structures: "add women and stir."[12] A parallel issue arises in relation to spirituality: does "add spirituality and stir" resolve its exclusion?

Thus, I was asking whether fundamental aspects of allopathic medicine and social science can be challenged, and if so, whether from within or without. This was my general interest, not specific to hospice or palliative care, and (so) I was also asking these questions in relation to my own attempt to apply social studies of STM reflexively; seeking to implement engaged social constructivist theories of knowledge and related methodologies in my own research practice, including "situating" my own knowledge.[13]

As noted, I began my fieldwork with a particular understanding of the development of the theory of social construction by engaged social constructivists; the position that this theory has consequences for the practices of all knowledge producers. I therefore sought to apply radical theories of knowledge production to my own production of knowledge, and I initially expected that these theoretical positions would also be relevant to my findings. However, as I proceeded through, and began reflecting on, my fieldwork I felt that I had identified a gap between theory

[10] Including both allopathic medical and social scientific knowledge.
[11] See, for example, Nicky James and David Field (1992), 'The routinization of hospice: charisma and bureaucratisation,' *Social Science and Medicine*, 34 (12): 1363-75.
[12] See Maria Mies (1983), 'Towards a methodology for feminist research,' pp. 117-39 in Bowles, G and RD Klein (eds.), *Theories of Women's Studies*. London: Routledge and Kegan Paul (later republished pp. 64-82 in Hammersley, M (ed.) (1993), *Social Research: Philosophy, Politics and Practice*. London, Newbury Park: Sage).
[13] Donna Haraway (1988), 'Situated knowledges: the science question in feminism and the privilege of partial perspective,' *Feminist Studies*, 14 (3): 575-99.

and practice for workers in St Z's, with which I was also struggling myself. I felt that I needed to find ways of understanding this, and so my question became not how people implemented radical theories in practice but what prevented them from doing so. In exploring ways of thinking about this, I investigated the work of other theorists of knowledge, before finally returning to Kuhn's work, and in chapter two I retraced the route which I followed.

I began by re-investigating two particular perspectives on the theory of the social construction of knowledge. One is that of theorists of the "disunity of science," who are interested in how people from different disciplinary communities communicate and work together by using concepts such as "trading zones,"[14] "standardised packages,"[15] and/or "boundary objects."[16] The other perspective is that of those theorists who focus on "science as practice," and argue that the implementation of theories in practice is not a straightforward process.[17] Scientists, they argue, cannot simply "extend the conceptual net" into practice, since they have to negotiate with the recalcitrances and resistances of the natural world in order to do so.

However, as I discussed in chapter two, I did not find either of these perspectives useful for understanding my findings. I therefore returned to re-read Kuhn, in particular his concept of the "disciplinary matrix," that is, his elaboration of the term "paradigm" in the sense of a "world view."[18] Kuhn claimed that the disciplinary matrix is the generally unquestioned intellectual context of a scientific community, within which scientists produce knowledge – both new theories and "normal science" (that is, elaborations and developments of existing theories). The

---

[14] Peter Galison (1996b), 'Computer simulations and the trading zone,' pp. 118-57 in Galison, P and Stump DJ (eds.) , *The Disunity of Science: Boundaries, Contexts and Power.* Stanford, CA: Stanford University Press.

[15] Joan Fujimura (1992), 'Crafting science: standardized packages, boundary objects, and "translation",' pp. 168-211 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

[16] Susan Leigh Star (1991), 'Power, technology and the phenomenology of conventions: on being allergic to onions,' pp 26-56 in Law, J (ed.), *Power, Technology and the Modern World.* Oxford: Blackwell.

[17] See for example, the collection edited by Andrew Pickering (Andrew Pickering (ed.) (1992), *Science as Practice and Culture.* Chicago and London: University of Chicago Press).

[18] Kuhn, op. cit., note 2.

disciplinary matrix of each scientific community comprises four kinds of elements: exemplars, symbolic generalisations, values, and metaphysical models. Values and metaphysical models are shared between disciplines, and are often less explicit than exemplars and symbolic generalisations, which are more particular to specific disciplinary communities.[19] New theories may have consequences for all of these elements, but most frequently new theories cause scientists to change some of their exemplars and symbolic generalisations, while leaving their values and metaphysical models unaffected.

Kuhn argued that when people (scientists) debate new and existing (scientific) theories, they use the same language but perceive the situations differently. This implies that the two groups' definitions of terms must differ. Kuhn argued that, in part because of this difference in perception, a new theory is incommensurable with an existing theory; that is, that people cannot simultaneously hold to both. Once someone has accepted a new theory, s/he can no longer hold to the preceding theory.

These differing perceptions means that groups must translate their different understandings of terms in order to understand one another. However, Kuhn argued that good reasons and translation are necessary but insufficient conditions for conversion of a person to a new theory. He claimed that to make a theory one's own 'one must go native,' that is, begin to think and work in the other language. But an individual cannot *choose* to make that transition; s/he may be fully persuaded by the new theory but unable to internalise it. S/he may therefore continue practising science on the basis of the old theory, perhaps adjusting the new theory to fit their existing understandings, a process which David Bloor calls "conventionalisation."[20]

I suggest that people are particularly likely to "conventionalise" new theories when such theories have consequences for metaphysical models and/or values, which are both more fundamental to the disciplinary matrix of their disciplinary community

[19] Kuhn argued that flexibility in how scientists interpret scientific theories occurs because scientists share values, rather than rules, for doing science, and different people who ascribe to the "same" values can apply them differently.

[20] David Bloor (1997), 'Remember the strong programme?' *Science, Technology and Human Values*, 22: 373-85.

and also (because) shared between the disciplinary matrices of multiple disciplinary communities. People's difficulties with fully internalising new theories are increased if those new theories challenge such fundamental and widely shared elements of disciplinary matrices.

I will now move on to recap the key findings from my fieldwork, discuss the relationship between them and other people's work, and reflect upon the relationship between my findings and the various theoretical positions which I have outlined above.

LOCATION AND MOVEMENT IN ST Z'S

In chapter four I showed that the various parts of St Z's were quite distinct from one another, and workers' practices varied between them. Associated with this there was a marked division of labour between workers, which was particularly apparent in case conferences. Nevertheless, some things were common across St Z's, and one such feature was that workers did not publicly discuss death and dying with patients or patients' relatives, and, indeed, often actively avoided such discussions.

In day care and St E's (the elderly care ward) this avoidance was associated with an emphasis on "cheering up" patients. So interactions between workers and patients in the public spaces in day care and St E's were generally light-hearted, with workers focusing on being cheerful and frequently changing the subject if patients raised "difficult" issues (such as issues related to death and dying). This was not necessarily a negative thing. Most people on St E's were there because, for various reasons, usually age-related, they were unable to live at home, not because they had been given a terminal diagnosis, while people in day care who did have such a diagnosis did not all want the same things from workers.

People who used day care varied widely in their physical health and length of time attending day care. They also varied in that some people wanted to be distracted from their disease and future death, whereas others wished to talk about these issues. However, of these opposed, contradictory wishes, workers chose to facilitate those of the former group of patients. That is, workers set out to distract and entertain

patients, and actively avoided talking with patients about death and dying. Any talk about death and dying when I was present was initiated by patients, and such talk usually occurred only when patients were together, apart from workers.

Similarly, Alison Langley-Evans and Sheila Payne state that in the palliative day care unit where Langley-Evans conducted fieldwork, talk about issues such as patients' illness, symptoms, treatment, loss of significant others, personal mortality, and deaths of other patients was usually initiated by patients, rarely by workers.[21] As I also observed in St Z's, workers usually spoke about such things only when they were responding to specific enquiries about a particular patient.[22] Langley-Evans and Payne also note (again, similarly to my observations) the "ongoing conversational banter" in this day care unit, and patients' use of jokes and facetious remarks in their talk.[23] However, in contrast to my observations, Langley-Evans and Payne argue that the light-hearted and humorous manner in which patients in this day care unit spoke about death enabled them to acknowledge their terminal condition, while distancing themselves from their (own) deaths.[24]

That is, Langley-Evans and Payne argue that humour *enabled* patients to talk about their illness, death and dying. Similarly, it has often been claimed that people with cancer can find humour helpful; even that humour can be therapeutic.[25] However, humour can also be used defensively, by both workers and patients, and it has also been argued that patients perceive others' attempts to "cheer them up" as

[21] Alison Langley-Evans and Sheila Payne (1997), 'Light-hearted death talk in a palliative day care context,' *Journal of Advanced Nursing,* 26: 1091-7: 1094.
[22] Langley-Evans and Payne, op. cit., note 21: 1094.
[23] However, Langley-Evans and Payne argue that humour was often conveyed by the context: the ongoing banter and people's use of innuendo or body language, and it was therefore not always easy to represent humour in discrete portions of transcribed talk (Langley-Evans and Payne, op. cit., note 21: 1096). Their discussion of the problems in representing "banter" also resonates for me with my experiences.
[24] Langley-Evans and Payne, op. cit., note 21: 1091.
[25] See, for example, Bellert JL (1989), 'Humor: a therapeutic approach to oncology nursing,' *Cancer Nursing*, 12 (2): 65-70; Hunt, AH (1993), 'Humour as a nursing intervention,' *Cancer Nursing*, 16 (1): 34-9; Bottorroff, J, Gogag, M and Engleberg-Lotzkar, M (1995), 'Comforting: exploring the work of cancer nurses,' *Journal of Advanced Nursing*, 22: 1077-84.

unhelpful,[26] and as minimising and/or preventing them from discussing their feelings.[27]

People may find it difficult to talk seriously in a situation where general "banter" and "light-heartedness" is the prevailing atmosphere, and it often seemed to me that both workers and patients in St Z's used humour to avoid talk of death and dying and to "block" discussion of potentially difficult feelings. Booth et al.[28] discuss "blocking" by nurses and claim that nurses use "blocking behaviours" most often when patients disclose their feelings, but that nurses' blocking behaviours decrease in frequency when they feel that they can get practical help if they need it, and that their direct supervisors are concerned about their welfare. This suggests that avoidance and blocking of discussion of issues which workers perceive as difficult or sensitive is more likely in situations where staff feel unsupported by their managers. As I discussed in chapter five, and mention in the chapter which is reproduced as appendix VI, this was indeed the case for some workers in St Z's, who were unhappy largely because they perceived that their managers were uncaring towards them.

"Going down/hill"

"Banter" and "carry on" was more evident in day care and St E's than in St P's (the palliative care ward). Nevertheless, workers on St P's also avoided public talk about death and dying. Linked to this, although I occasionally heard patients using the words "death" or "dying," I never heard any workers in any part of St Z's using these words in relation to living patients, even when they spoke privately about their perceptions that particular patients were likely to die in the near future. When someone had actually died, however, workers sometimes used the word "died," usually in a lowered voice, at times almost a whisper.

Both workers and patients in St Z's usually conveyed their perceptions that someone was likely to die in the near future in an indirect way, by using one of two

[26] Holly Peters-Golden (1982), 'Breast cancer: varied perceptions of social support in the illness experience,' *Social Science and Medicine*, 16: 483-91.
[27] Camille B Wortman (1983), 'Social support and the cancer patient: conceptual and methodological issues,' *Cancer*, 53 (10): 2339-62: 2347-8.
[28] K Booth, PM Maguire, T Butterworth and VF Hillier (1996), 'Perceived professional support and the use of blocking behaviours by hospice nurses,' *Journal of Advanced Nursing*, 24 (3): 522-7.

similar phrases: "going down" or "going downhill." These metaphors enabled them to describe an abstract concept, and Lakoff and Johnson[29] argue that metaphors, particularly spatial (physical) metaphors, are common for such concepts.[30]

As I discussed in chapter four, when people in St Z's used these "going down" or "going downhill" metaphors they were expressing something rather more subtle than that someone was "dying." To some extent it would have been meaningless to say that particular patients were "dying," since every palliative care patient could be said to be dying, in the broad sense that they all had an incurable disease, yet some people with a "terminal" diagnosis can be relatively well and live for years.[31] "Going down/hill" phrases emphasised the perception that a particular person had changed in some way, such that their death was likely to occur in the near future, while avoiding the potential problem of inaccurately estimating exactly when that person was likely to die[32] (so, too, I use the paraphrase "near future" rather than "soon"). The inaccuracy of these estimates would have been more evident if people had said that someone was "dying," and then that person did not die, than if that person was said to be "going downhill," which had a more gradual implication, associated with a vague time scale.

Perhaps, therefore, the use of metaphor by people in St Z's was unavoidable, and the metaphors which people in St Z's used were not entirely or solely euphemistic, since they conveyed a meaning which an apparently more explicit word such as "dying" does not convey. However, these metaphors were still in part euphemistic, since, by using them, people avoided explicitly referring to death or dying.

Lakoff and Johnson claim that DOWN has a negative association, and DOWN metaphors are often used for negatively perceived events. Thus, the metaphors of "going down" or "going downhill" have a particular sense of negativity which is not

[29] George Lakoff and Mark Johnson (1980), *Metaphors We Live By*. Chicago and London: University of Chicago Press.
[30] So, for example, Cicely Saunders' phrase: "we moved out so the knowledge could move back in" is also a metaphor of movement.
[31] Thus, the distinction between them and other people is less clearly defined, since, as I noted in chapter four, in a sense we are all dying, since "life is a terminal diagnosis."
[32] This is not, of course, to say that workers *intentionally* used these metaphors to this end.

present in all metaphors for dying (see, for example, the phrase "fading away," which, while it also expresses the sense of movement elsewhere, is less strongly negative).[33] The only person in St Z's who I ever heard using a phrase which was not a DOWN metaphor was Sr 13, who used the phrase "getting weaker." However, I never actually heard Sr 13 using this phrase in conversation with others, only in conversation with me, when she discussed her deliberate use of this phrase to avoid what she perceived as workers' frequent use of language with negative connotations when speaking about patients who were less well. "Getting weaker" was less negative than "going down/hill," but had an equally vague sense of time; implying that a patient was likely to die in the "near future," but (as with "going down" and "near future") conveying no definite sense of when.

Physical location and movement

Workers' and patients' use of metaphors of movement for their perception that someone was getting closer to death paralleled the importance which both patients and workers attached to patients' actual physical location and movement within St Z's. Single rooms on St P's were allocated (if at all possible) to people who were particularly unwell and/or who workers perceived as "going downhill." Workers perceived moving these patients into single rooms as something which both benefited the particular person involved, and also benefited other patients (since these patients

[33] Joanne Chekryn Reimer, Betty Davies and Nola Martens (1991), 'Palliative care: the nurse's role in helping families through the transition of 'fading away,'' *Cancer Nursing*, 14 (6): 321-7. Other spatial metaphors which could be used to convey the sense that someone was getting closer to death include "progressing," "advancing," "moving forward," "going along," "getting deeper." "Progressing" and "advancing" are often used in relation to cancer (the disease itself), and are therefore strongly associated with disease rather than with people (see Susan Sontag (1979), *Illness as Metaphor*. London: Allen Lane, and also (1989), *AIDS and its Metaphors*. London: Allen Lane). It would therefore seem strange if people in this context used these metaphors in relation to a person. These words also convey a sense of positive continuation or development, rather than negative change (although this is paradoxical in relation to a developing cancer), as does "moving forward," while "going along" conveys the sense of a steady state, so might seem strange used in this context. "Getting deeper" is a phrase which, as I have noted, was used in St Z's (and elsewhere) for emotion and/or spirituality. In addition, this phrase conveys a sense of movement within oneself, so would not seem to fit with dying.

would then not witness the person's death and/or distress, and so, workers felt, their own distress would be prevented).[34]

Conversely, palliative care patients who were no longer able to live at home, but who workers perceived as *un*likely to die in the near future were moved from St P's to St E's, where they were given single rooms. Again, this movement was related to workers' perceptions of the likely length of life of the particular patient involved. Palliative care patients were given single rooms on St E's, rather than beds on the shared wards, because if they were placed in shared wards they would be sharing the space with elderly care patients. Workers expected elderly care patients to live much longer than even these relatively long-lived palliative care patients, and felt that elderly care patients would be distressed if people repeatedly died in their rooms.

However, not all palliative care patients who were expected to live for a relatively long period of time were moved to St E's. As I discussed in chapter four, Jimmy M was on St P's for a long time, for much of which time his health was relatively stable, and so he was not given a single room on St Ps. Nor, however, was he moved to St E's, because workers perceived St E's to be populated with "old" people, and so to be inappropriate for Jimmy, who (being in his early 50s) was "still a young man." Workers found situating Jimmy M difficult, and this highlighted the normal pattern of location and movement for people in St Z's, which Jimmy's situation disrupted.

Patients' physical location in the hospice was also important for people in day care. For them, phrases such as "he's gone upstairs" or "she's upstairs" had a particular resonance. These "upstairs" phrases meant that the person had been admitted to a ward, which was a significant change from their usual situation (of living at home and periodically visiting day care),[35] and so these phrases implied that

[34] Thérèse M Mazer also observed this in the Edinburgh hospice which she studied (Mazer (1994), 'Death and dying in a hospice: an ethnographic study,' unpublished PhD thesis, University of Edinburgh). On the other hand, Sheila Payne et al. (Sheila Payne, Richard Hillier, Alison Langley-Evans and Tony Roberts (1996), 'Impact of witnessing death on hospice patients,' *Social Science and Medicine*, 43 (12): 1785-94) argue that patients who witness other patients' deaths are less distressed than those who do not.

[35] If day care patients were admitted to the wards for respite care, people in day care explicitly stated this, so distinguishing respite patients from other patients on the wards, who were merely stated to be "upstairs," with all the resonances which that held.

the person concerned was getting closer to death. Thus, people in day care associated the physical location of "upstairs" with being closer to death.

Nevertheless, people in day care used the same DOWN metaphors as other people in St Z's when they spoke about patients getting closer to death. Thus, for people in day care, patients' physical location and movement was highly significant, but did not correlate with the metaphors of movement which they also used. So, although if someone had "gone upstairs" people in day care understood this to mean that s/he was less well, they said that s/he was "going down/hill" *not* "going up."

So, to summarise, location and movement, both physical and metaphorical, was highly significant for people in St Z's. Patients' presence on particular wards, and the rooms they were allocated on those wards, were associated with workers' (and patients') perceptions of how close patients were to death. Death and dying were located elsewhere, both literally (occurring in private, not in shared spaces) and metaphorically, which often had strongly negative associations. This association of particular kinds of literal and metaphorical location and movement with death and dying (an association which patients also made) was reproduced in talk about death and dying – which also occurred outside shared spaces. The attitude of many workers in St Z's towards death and dying was such that in public spaces they emphasised "cheering up" patients and generally sought to avoid talking with patients or patients' relatives about issues related to death and dying. Of itself workers' avoidance of public talk about death and dying did not necessarily imply an absence of spiritual care (although attention to end-of-life issues might seem to be integral to spiritual care[36]), but workers avoided public talk about all kinds of "deep" issues.

[36] Pam McGrath (2002), 'Creating a language for 'spiritual pain' through research: a beginning,' *Supportive Care in Cancer*, 10: 637-46.

THE SPIRITUAL ASPECTS OF CARE

Although, as I have noted, there were clear distinctions between the various parts of St Z's, the atmosphere throughout St Z's seemed to me to be generally caring. Most workers were attentive to and focused on patients, and gentle and kind in their interactions with them, such as when helping people to eat. Workers frequently said that what they did was "more than just a job," and referred to their approach as "TLC" (tender loving care), while many nurses additionally talked of what they did as being "good nursing practice." All the nurses in St Z's had been trained in hospitals, and several nurses said that they had been attracted to St Z's by the opportunity it offered of doing "real nursing." Many nurses told me that they had come to St Z's because they felt that it was possible to carry out "good nursing practice" there, and nurses frequently distinguished between hospitals and St Z's on this basis, saying that it was difficult, if not impossible, to carry out good nursing practice in hospitals.[37] They felt that in St Z's they were able to nurse in a way which matched what they felt they had been trained for, which they did not perceive to be possible in hospitals.

However, even though the noticeably caring atmosphere in St Z's might seem to suggest that a spiritual dimension was present, I became increasingly uncertain whether the spiritual aspects of care were present in St Z's. It did not seem to me that "good nursing practice" was unique to St Z's, and, as my fieldwork progressed I found it difficult to identify any aspects of care which seemed to me to be specifically spiritual (as distinct from, for example, emotional).

It did seem to me, however, that the caring of a few workers had something extra; that there was a different quality to the way in which these people interacted with others (not only patients and their relatives but all people in St Z's (including me and their co-workers)). Many people in St Z's recognised this intangible something in the approach of these particular workers, but most people (including myself) struggled to characterise it when I asked them to do so, and could only say

[37] Owing to the emphasis in hospitals on "busyness" and "getting the work done," which prevented them from spending time with patients.

that perhaps these people were particularly loving and attentive. I wondered whether the distinctive quality of these particular workers' interactions with people was perhaps related to the spiritual aspects of care, and so, as my fieldwork progressed, I aimed to interview all of these workers.

However, in my taped interviews with workers, I found that few workers identified any specifically spiritual aspects to care, or claimed that they personally gave care which had such aspects. Even those workers who identified that there was a particular quality in how they and/or other workers interacted with other people, did not necessarily equate this with the spiritual aspects of care.

"It's not my job"

So, most workers in St Z's did not perceive that their work involved anything spiritual. Although workers generally stated that the spiritual dimension of care was important, and they were aware that it was part of the philosophy of hospice care, few workers felt that they personally were expected to, or competent to, deliver spiritual care. They perceived that attention to patients' spiritual needs was someone else's responsibility, although they were vague about whose responsibility this was.

The sense that particular people were responsible for particular things was a powerful one for workers, who had a strong sense of what was a "job," and of what their jobs did and did not entail.[38] Workers across St Z's frequently used phrases such as "that's not my job" or "I'm not qualified," and they all seemed to have a strong sense of where the boundaries of their professional roles lay, and of the expertise, responsibility and autonomy associated with particular roles. Workers' strong sense of what their jobs were linked to their distinct locations in different parts of St Z's, since the different parts in St Z's were associated with the perception that there were different "kinds" of patients in each place, with different kinds of needs, and the division of labour between members of the "multi-disciplinary team" meant that different "kinds" of workers met different kinds of needs. In turn, this linked to workers' differing perceptions of spiritual care.

[38] This sense of what a job was and what it was not was also apparent in the often-used phrase that work in St Z's was "more than just a job" (see above).

Thus, day care workers did not perceive that spiritual care happened in day care; none of these workers felt that they gave such care, or that they were competent to give it. DCC 14 (the day care manager) explicitly said that the spiritual aspects of care were "not my job," although her background was in occupational therapy and she talked about how her training had emphasised an holistic, contextual understanding of patients' needs.

Few workers on St E's claimed to give spiritual care. Although many nurses on both St E's and St P's said that their work in St Z's was "more than just a job" and identified what they did as "good nursing practice," few nurses on either ward claimed that they understood or personally provided spiritual care. Only one nurse on St E's (SN 2) and three nurses on St P's (SN 16, SN 17 and SN 25) told me that they had a sense of what spiritual care was, and they had different understandings of what it was, and of whether they personally provided it.

Four workers who were not specifically associated with any single part of St Z's (HCC 11, SW 12, Sr 13, and Dr 21) told me that they felt that they gave or tried to give spiritual care, and/or had a sense that this kind of care had a particular content, involving an active engagement with patients' spiritual concerns and/or questions. Three of these workers, HCC 11, Sr 13 and Dr 21, were at high levels in the hierarchy of the hospice (medical consultant and deputy matron), and so were relatively autonomous. However, not all workers in such positions claimed to provide spiritual care; the medical director (Dr 5) did not. Dr 5 told me that he felt that his role was to address patients' physical issues, while someone else addressed spiritual issues.[39]

So, although workers who were at a high level in the hierarchy of the hospice perhaps had the freedom to expand the explicit boundaries of their professional

[39] Dr 5's abstention from the non-physical aspects of care is similar to Nicky James's findings in her study of hospice care (James (1986), 'Care and work in nursing the dying,' unpublished PhD thesis, University of Aberdeen); see also Nicky James (1992), 'Care = organisation + physical labour + emotional labour,' *Sociology of Health and Illness*, 14 (4): 488-509: 503, where she quotes the medical director's statement that he was 'no good at that kind of thing.' However, James suggests that there was almost an inverse law of status and skill in emotional labour, which in her study she identifies as being carried out predominantly by four older nursing auxiliaries, and what I found in relation to the spiritual aspects of care in St Z's was not as clearly demarcated as this.

roles,[40] the delivery of spiritual care was not simply associated with such positions. Nor, although both Dr 21 and Sr 13 moved freely between the various parts of St Z's, was this freedom of movement necessarily associated with the provision of spiritual care. Both the social workers moved between the different parts of St Z's, but only SW 12 claimed to provide spiritual care, and, although she said that she thought that spiritual care was important, she felt (as did SW 10) that her main focus was meant to be on issues such as facilitating the provision of home aids, financial assistance and benefits, and supporting families (for example, through the weekly drop-in group for bereaved children). She therefore found it difficult to find time to give spiritual care at a time when patients wanted it.

Thus, very few workers in St Z's felt that they personally gave care which had spiritual aspects, and these workers did not have similar professional roles or positions within the hospice. Those workers who identified the spiritual aspects of care as relating to care with a particular content were mostly people who had religious beliefs (although they all distinguished between spiritual and religious care[41]), but not all. Nor did all workers with religious beliefs equate the spiritual aspects of care with a particular content to care – SN 2 equated them with her manner of delivering care.

Those workers who equated the spiritual aspects of care with a particular content to care all located the spiritual somewhere elsewhere than the immediately apparent or day-to-day, and identified the spiritual aspects of care as being additional to or outside their usual work. The only exception to this was Dr 21, who talked about his plans to make this kind of care part of his daily practice. But he was

[40] See also Arlie Hochschild's comment that people with higher status are permitted to express their emotions, and do not have the obligation to manage them which people with lower status have (Hochschild (1983), *The Managed Heart: Commercialization of Human Feeling*. Berkeley, Los Angeles, London: University of California Press).

[41] This was not the case for people who were solely religious professionals, thus, Fr 18 conflated spiritual and religious issues, unlike Sr 13 who clearly distinguished between them.

explicitly choosing to do this as an additional thing; no one else perceived this as intrinsic to his role.[42]

So, in St Z's – contrary to general hospice rhetoric and promotional and training literature in St Z's – the spiritual aspects of care were not integrated with the other aspects of care, but were marginalised and individualised. Most workers in St Z's had no understanding of the spiritual aspects of care; those few who did differed in their understandings of what these aspects of care entailed. Not all patients would have contact with these few workers, and, since these workers varied in their understandings of the spiritual aspects of care, patients' spiritual concerns and questions were not necessarily engaged with.

Perhaps, therefore, some patients' spiritual needs were not addressed, but I have no direct evidence for this, since (as I have noted in earlier chapters and in the chapter which is appended as appendix VI), I decided not to interview patients, precisely because I was uncertain of whether patients' spiritual needs were being addressed.[43] I do perhaps have indirect evidence, though, because (as I discuss later in this chapter) as I was coming to the end of my fieldwork the managers employed a pastoral care coordinator, who was to provide spiritual care for both patients and workers. This suggests that while I was doing my fieldwork the managers did not feel that spiritual care was adequately provided in St Z's (as I also discuss later).

"Getting deeper"

Linking to the general perception that the spiritual aspects of care were part of someone else's job and occurred outwith daily practice, workers never explicitly discussed spiritual (nor religious) issues for patients in public situations such as ward meetings or informal conversations. This was also the case in the weekly case conferences, where workers discussed the physical issues which they felt affected patients, and also considered emotional, psychological, and social issues. They always also talked about patients who had died in the previous week, and in these

[42] Note that Dr 21 had sufficient autonomy to be able to augment his role in this way; although, since no boundaries drawn, since the spiritual aspects of care were so unclearly defined, other workers could perhaps have done so too.

[43] See my later discussion of expertise and reflections on the research process.

discussions they frequently commented that a patient and/or their family "did well." It is possible that in their use of this phrase workers were referring obliquely to spiritual or religious issues, but they never elaborated on these statements to explain or discuss in what way the person had "done well."[44]

As noted, most workers did *not* have any concepts of spirituality and/or spiritual care, while most of those workers who I knew (having discussed this with them in one-to-one interviews and/or conversations) had religious and/or spiritual beliefs and/or thought about spiritual care did not discuss these issues openly with other workers. Many were reticent even on a one-to-one basis, and several of those who discussed their beliefs with me asked me to reassure them that what they were saying was confidential. The only worker who I ever heard discussing these issues in public was SN 25, the night sister on St P's, and she did not do this often.[45]

One nurse on St E's: SN 2 told me that she felt that spiritual care was part of what she did. For her, the spiritual aspects of care related to her attitude towards her patients; these aspects of care related to the love with which she felt that she delivered all the care which she gave, saying: "you just love them, you just do." A few other workers – on St P's, and across St Z's – understood the spiritual aspects of care differently, as relating in some way to a particular action: "going deeper," which in some way involved "getting closer" to patients.

Thus, in the talk of these latter few workers, the use of metaphors by people in St Z's which struck me in relation to dying was also evident. They all used spatial metaphors to talk about spirituality, speaking of a person's spirit as being in some way elsewhere: "beneath," "beyond," "deeper," or "inside." A couple of workers also stated that the spiritual dimension of a person was "What you get to after everything else has been taken care of" or "What's left after everything else has been stripped away." These latter metaphors, while slightly different from the beneath and beyond metaphors, still indicate the sense that the spiritual dimension is somehow

[44] Unfortunately I did not explore this at the time; it was something which only occurred to me after I had completed my fieldwork.

[45] A possible factor in SN 25's openness about such issues was that she had some years previously been a nun, which was generally known to other workers.

concealed by "everything else," that is, that it is not immediately apparent, and is metaphorically DEEP.

That is, the few workers in St Z's who told me that they had a concept of spiritual care generally had the sense that spirituality was within a person – within their body – and/or concealed by other things. This then implied that spiritual care – reaching a person's spirituality – involved removing these other things, perhaps layer by layer. Since spirituality is DEEP within, it is reached last.[46]

"Getting deeper" implies the metaphoric movement away from HERE (day-to-day, "normal" life), and also the possibility of accompanying the person in that movement. However, workers perceived that going DEEP was difficult: "as you get deeper it gets harder," and they therefore chose whether to go DEEP with particular patients, and also chose how deeply they were willing to go, that is, the extent to which they were willing to pursue issues (or, in Sr 13's terms, move through the levels: how are you? how are *you?* how are ***you?***)[47]

Thus, those St Z's workers who identified spirituality metaphorically located it elsewhere. Associated with this, they felt that a metaphoric movement was necessary to reach patients' spirituality. For them, this movement required time and often (that is) effort. This effort was also apparent for workers when they tried to talk about spirituality with me. In interviews, these workers seemed to me to be trying to help me by trying to find ways of talking about the spiritual aspects of care, yet struggled to do so. They also talked about the difficulty and effort of talking about such issues with patients, and so it seemed to me that talking with me about spirituality was similar to doing so with patients. Perhaps this was because workers were talking about something (spirituality) which they constructed as elsewhere, and

[46] Thus, although workers identified the spiritual aspects of care as important, the order of addressing patients' needs meant that these aspects of care came last, which suggests that they might not happen, since, as discussed, patients' situations could change rapidly, and so there might not be time to "get to" a particular patient's spiritual needs. See Celia Davies' discussion of what she calls the "Polo mint problem," and her argument that the professionalisation of nursing has led to a situation whereby non-technical nursing, which she considers the most important element of nursing, "drops through the middle," since technical elements are prioritised (Davies (1995), *Gender and the Professional Predicament in Nursing*. Buckingham and Bristol, PA: Open University Press).

[47] As noted in chapter five, Sr 13 physically conveyed the DEEP metaphor via her increasing emphasis, with her voice becoming deeper and stronger with each repetition of this phrase.

(therefore) as taking effort to reach.[48] The only workers who did not struggle to talk about their understandings of spirituality and the spiritual aspects of care were SN 2, Dr 21 and Sr 13, all of whom had strong religious beliefs, and associated understandings of spirituality.

The Australian theorist Regina Milard (an ex-nun) also uses a metaphor of movement, and conveys a sense of the difficulty associated with this movement, when, in her discussion of the delivery of spiritual or pastoral care, she states that "Compassion is difficult because it requires the inner disposition to *go with others to the place where they are weak, vulnerable, lonely and broken.* This is not our spontaneous response to suffering. We prefer to *flee from it* or find a quick cure for it [...] keeping busy and feeling relevant"[49] (my emphases).

So Milard also uses metaphors of location and movement, and for her, as for workers in St Z's, it is difficult to "go with others" from HERE to that "weak, vulnerable" place, and people prefer to "flee" from the difficulty. "Flee" also implies fear, in the same way as SN 17's comment that people want to "run away" from difficult questions. These difficult questions were ones to which SN 17 felt that workers had no answers, and I suggest that this raises issues to do with uncertainty, which link to the question of expertise (I return to this point later).

Perhaps the fear and uncertainty of workers in St Z's also related in part to the conceptually close metaphors of DEEP and DOWN. Workers' use of DEEP metaphors for spirituality or "the spiritual" coexisted with the use by many people in St Z's of metaphors of moving DOWN to express their perception that someone was likely to die soon. Death was DOWN, and so dying involved moving DOWN, away from HERE, and DEEP also conveys a strong sense of going elsewhere than HERE. So, for workers in St Z's, HERE was the surface from where people go somewhere else – DOWN or DEEP – and so perhaps accompanying someone DEEP had resonances with the negative associations of DOWN. We are all vulnerable, since we will all eventually

[48] Their metaphorical understanding of the effort involved in "going deep" with patients to reveal the not immediately apparent was paralleled in my own efforts to seek out the not immediately apparent – the spiritual aspects of care – and "digging" for them in interviews.

make that movement DOWN to that uncertain place, and that vulnerability and uncertainty is perhaps exposed by going DEEP. That is, accompanying people to the place where they are vulnerable touches on one's own vulnerability.[50]

The use by people in St Z's of metaphors for spirituality is not unusual, since spirituality is often associated with metaphor,[51] and referred to as being innately metaphoric, such that it can only be talked "about" – in the sense that it can only be circled around, pointed towards, but never directly conveyed.[52] Further, as with the metaphor of "going down" which people in St Z's used to convey the sense of an increased likelihood of someone dying, the "getting deeper" metaphor which they used for spiritual issues was not unique to them. So, for example, Ruth Stoll (a nurse) has developed a model which (similarly to other, often used constructions) depicts a person as a succession of concentric circles, with "biological" as the outermost circle, "will" within that, and "spirit" within that (figure 6.01).[53]

[49] Regina Milard (2002), 'Facing the situation,' pp. 97-115 in Rumbold, B (ed.), *Spirituality and Pastoral Care: Social and Pastoral Perspectives*. Melbourne, Oxford and New York: Oxford University Press: 110.

[50] See also Len Lunn (1990), 'Having no answer,' in Saunders, C (ed.), *Hospice and Palliative Care*. London: Edward Arnold, and Tony Walter's discussion of the centrality of vulnerability to Christian and Buddhist approaches to the care of dying people (Tony Walter (1997), 'The ideology and organization of spiritual care: three approaches,' *Palliative Medicine*, 11: 21-30).

[51] Rachel Stanworth (1997), 'Spirituality, language and depth of reality,' *International Journal of Palliative Nursing*, 3 (1): 19-22.

[52] So, for example, in relation to Taoist thought, the *Lao Tzu* opens by stating that: "The way that can be talked about is not the constant way," and, as DC Lau discusses, this is because language is inadequate to describe the *tao* (Lao Tzu (translated and introduced by DC Lau) (1963), *Tao Te Ching*. Harmondsworth: Penguin: 15-16).

[53] Ruth I Stoll (1989), 'The essence of spirituality,' pp. 4-23 in Verna B Carson (ed.) *Spiritual Dimensions of Nursing Practice*. Philadelphia and London: WB Saunders, citing the model she developed with Stallwood (Stallwood, J and R Stoll (1975), 'The spiritual dimension of nursing practice,' in Beland, IL and JY Passos (eds.), *Clinical Nursing*, 3rd edition, New York: Macmillan).

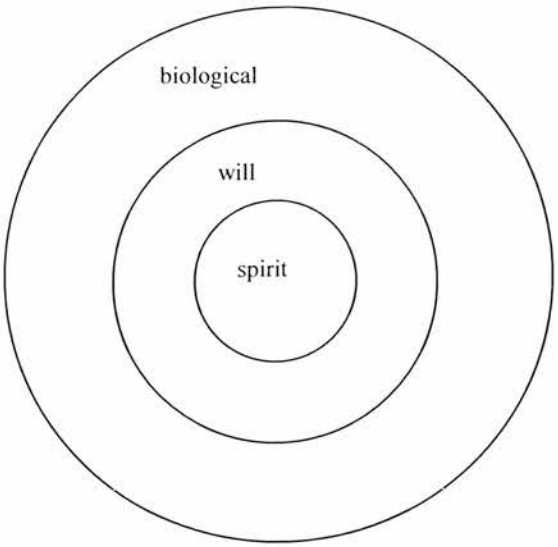


Figure 6.01:
Ruth Stoll model

This is a similar construction to that of Rob George (a consultant in palliative care), whose model represents a person as an egg, with three layers: "thinking" (immediate issues) on the surface, "feeling" (emotional issues) beneath that and "being" (spiritual issues) within that, the core (figure 6.02).[54]

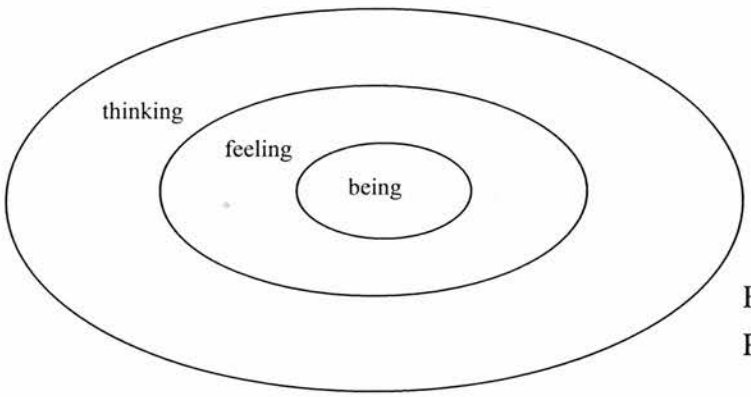


Figure 6.02:
Rob George "egg" model

In a related field, Michael Anderson discusses the use of the metaphor of depth by bereavement counsellors in the UK, and, in his consideration of this, he also builds on Lakoff and Johnson, in particular their argument that the metaphor of DEEP is

[54] Nina Swire and Rob George (1997), 'The "egg" model,' paper presented at Spiritual Dimensions of Health Care conference, British Holistic Medical Association, London, October 1997.

premised on the metaphor of self as CONTAINER. Anderson argues that, for bereavement counselling, the person is conceptualised as a receptacle of selves, with the true self being "inside" the person, and eventual contentment lying somewhere "deep within" them. The role of the counsellor is to help the person by "getting inside them" or helping them to "get inside" themselves.[55] This is paralleled by Dr 5's comments in chapter five (transcript 5.05, lines 22-23): "perhaps there is ego, a thin layer of emotion and a deeper spiritual self; [*spiritual care is*] getting beneath the skin."

Thus, the way in which those St Z's workers who had concepts of the spiritual aspects of care constructed and conceptualised them was not unique to them, but related to a wider social/cultural understanding (both lay and allopathic medical), whereby spirituality is located within, beneath, or beyond what is immediately apparent. This understanding in turn links to the concept of people as comprising separate levels or layers, of which spirituality is the DEEPest, and to the idea that these layers therefore need to be removed in order to reach a person's spirituality. This is also implied in the way in which a few St Z's workers conceptualised the spiritual as "what is left," a conceptualisation which similarly separates the spiritual from other parts of the person. As Marjory Byrne argues, conceptualising the spiritual as what is left over when the body or mind have been removed, suggests a triangular rather than a holistic approach, where body, mind and spirit are considered to be separate compartments of knowledge and understanding.[56] (See my discussion of allopathic medical understandings in chapter two).

Workers in St Z's therefore used a similar metaphor to that present in the wider culture when they metaphorically located spirituality inside or deep within a person and/or underneath, beneath or beyond something else. Although each of these metaphors locates spirituality in a slightly different place relative to HERE, they all convey a similar sense of a person's spirituality as being elsewhere and separate from

[55] Michael Anderson (2001), "'You have to get inside the person' or making grief private: image and metaphor in the therapeutic reconstruction of bereavement,' pp. 135-43 in Hockey, J, Katz, J and N Small (eds.), *Grief, Mourning and Death Ritual*. Buckingham: Open University Press.
[56] Marjory Byrne (2002), 'Spirituality in palliative care: what language do we need?' *International Journal of Palliative Nursing*, 8 (2): 67-74.

the other parts of themselves: within a person, covered and/or concealed by other things, and also (therefore) private and individual. Workers also conceptualised the spiritual aspects of care as elsewhere; either part of someone else's job, or, if part of their own job, as not present or evident in the same way as physical or even emotional care (although, again similarly to the models above, they conceptualised emotional needs as not immediately apparent, although less DEEP than spiritual needs). If spirituality and the spiritual aspects of care are located elsewhere, the choice can be made to go to that other place or not.

In contrast to this understanding of the spiritual aspects of care, and to the models I have illustrated above, consider the "4S" model of the human being developed by Robert Twycross (an early pioneer of the modern hospice movement/palliative care) (figure 6.03). Twycross' model also uses circles to indicate the various dimensions of a person, but in his model "the spiritual dimension embraces and integrates the physical, psychological and social dimensions."[57] This model could seem closer to the theory of total pain/care, but it is unclear how it translates into practice, and in his book Twycross includes spiritual care in a chapter on "psychosocial issues," which seems to imply that the spiritual is subsumed in psyche and social, that is, the reverse of his pictorial model.[58]

[57] Robert Twycross (2003, 4th edition), *Introducing Palliative Care*. Oxford: Radcliffe Medical Press: 39.

[58] See Allan Kellehear's discussion of the blurring of spiritual and psychosocial in contemporary palliative medicine (Allan Kellehear (2000), 'Spirituality and palliative care: a model of needs,' *Palliative Medicine*, 14: 149-55) and Tony Walter's consideration of articles which identify the "search for meaning" as a 'psychosocial' issue, and the concern he expresses that, without vulnerability and love, spiritual care will be reduced to good listening skills and so become indistinguishable from emotional/psychological care (Tony Walter, op. cit., note 48: 26; 28). Also see David Field (2000), 'What do we mean by 'psychosocial'? A discussion paper on use of the concept within palliative care,' London: National Council for Hospice and Specialist Palliative Care Services.

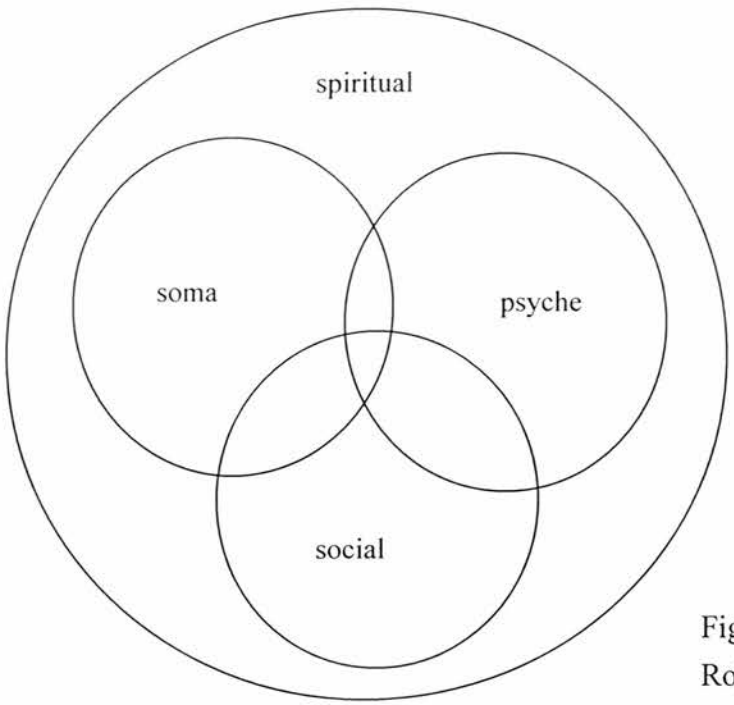


Figure 6.03:
Robert Twycross "4S" model

REFLECTIONS ON THE RELATIONSHIP BETWEEN THEORY AND PRACTICE

I was originally looking for the relationship between the theory of total pain/care and the practices of workers in a particular hospice (St Z's), and I think that at the outset I was, on some level, expecting to find such a relationship. However, as I have outlined, it increasingly seemed to me that there was a gap between the two, such that, although workers were aware of the philosophy of holistic or "total care," the practices of individual workers did not necessarily reflect the whole of the theory of total pain/care.

Most workers in St Z's seemed to me to be extremely caring towards patients, and most were aware that the philosophy of the (modern) hospice movement related to a kind of holistic care, which included attention to a spiritual dimension. Most claimed that this philosophy was reflected in practices in St Z's. In particular, most workers stated that the spiritual aspects of care were important, and said that they

occurred in St Z's. However, practices varied across the hospice, and workers differed in their understandings of what the spiritual aspects of care involved, with few workers claiming that they themselves gave care which they would define as spiritual. Most workers identified the spiritual aspects of care as someone else's responsibility.

Those few workers who claimed that the care which they personally gave had spiritual aspects understood these aspects in one of two ways. SN 2 identified the spiritual aspects of care as being "TLC" (tender loving care), or her loving attitude towards patients. That is, for SN 2 the spiritual aspects of care were the manner in which she tried to deliver the care which she gave. However, many other workers in St Z's also said that what they did involved TLC and caring attention to the person as a whole person (which many nurses called "good nursing practice"), but, unlike SN 2, they did *not* usually consider that this was spiritual care.

The remaining few workers who claimed that they could identify spiritual aspects of care said that these related to a particular *content*, that is, something more than the manner in which patients were cared for, which related to a specific action: choosing to accompany the patient in "going deeper." That is, in some sense "**doing** caring, relating to an action, as opposed to an attitude "**being** caring." That is, as I discussed in chapter five, an active "being with"[59] as opposed to a passive loving attitude: "just being." Since the action of "going deeper" was an action, which often/usually required a particular effort, these workers did not all always feel able to give such care.

Workers in St Z's did not publicly discuss their differing positions on spiritual care, however, so workers' various understandings of spirituality were seldom explicitly shared with each other. This silence about spirituality (like that about death and dying) could suggest that workers' understandings were individual, not collective. However, I suggest that a collective understanding of the spiritual

[59] For example, Linda Ross (1998), 'The nurse's role in spiritual care,' pp. 119-35 in Cobb, M and Robshaw, V (eds.), *The Spiritual Challenge of Health Care*. Edinburgh and London: Churchill Livingstone. Also see Linda Ross (1994), 'Spiritual aspects of nursing,' *Journal of Advanced Nursing*, 19: 439-47.

aspects of care (and of death and dying) was, effectively, constructed, precisely through and by that silence.

Both workers and patients tacitly shared the understanding that spirituality, death and dying were not to be discussed publicly, and were (thus) apart from (marginal to) the day-to-day. Related to this, most workers did not identify the spiritual aspects of care as part of daily practice. This was the case both for the majority of workers, who did not consider that these aspects of care were part of their own practice, and also for those workers who did, but who understood these aspects of care to be instrumental. For these latter workers the spiritual aspects of care were additional to their usual daily practice (elsewhere; "beyond" or "beneath" other things). Only those few workers who perceived that these aspects of care were (solely) expressive conceptualised them as part of their daily practice. Nevertheless, they still did not feel able to discuss these things with other workers.

In this way, although many workers in St Z's identified the spiritual aspects of care as being, if not the most important aspect of hospice care, certainly one of the most important, these aspects of care were delivered by a minority of workers, were understood to mean different things (even by this small group of workers), were not publicly discussed, and tended to come "after everything else has been taken care of."

The perception of most workers that the spiritual aspects of care were elsewhere – in a different place, not part of (their) daily practice, and/or, for many workers, in someone else's job – was an accurate one in that these aspects of care were not explicitly identified as the responsibility of any particular worker, or any particular professional role. None of the workers whose work was not religious had received any training in spiritual aspects of care. Those workers who felt that they gave spiritual care, therefore, had taken on this responsibility informally. Thus, too, the spiritual aspects of care were individualised,[60] and, therefore, variable in nature,

[60] See Lisbeth Thoresen (2003), 'A reflection on Cicely Saunders' views on a good death through the philosophy of Charles Taylor,' *International Journal of Palliative Nursing*, 9 (1): 19-23 for a discussion of the individualism implied in Saunders' views of a good death; see also Tony Walter's comment that the equating of spirituality with an individual search for meaning exists within a postmodern culture that distrusts any authority outside the self (Walter, op. cit., note 48: 26).

and (since most workers did *not* feel that there were spiritual aspects to the care which they provided) might not occur at all.

The framework which I had adopted for my fieldwork was engaged social constructivism, a way of making excluded knowledges visible, and I did not find that this helped me very much in understanding the findings I have summarised above. As I proceeded through my fieldwork, and while writing about it, therefore, I explored different positions from social constructivism which might offer insights.

In the early stages of my fieldwork I wondered whether St Z's could be thought of as a "thought collective," in Fleck's sense.[61] However, I gradually began to think that St Z's was not a single place, but rather a collection of several, relatively self-contained places. As noted, workers' practices differed between these different places, and their understandings of what hospice care involved (especially of its spiritual aspects) also differed, not only between the different parts of the hospice but also between workers in each part. Thus, St Z's did not seem to me to be a single physical community, nor a single thought collective, since workers did not share a single set of understandings particular to St Z's (or indeed to hospices generally), other than the tacit agreement that death and dying and the spiritual aspects of care were not to be openly discussed. Workers in St Z's seemed to me to belong to multiple thought collectives, relating to their professional backgrounds (or disciplinary communities) rather than a single one relating to hospice.

I therefore next explored whether the concept of "trading zone" was relevant to St Z's. Galison and others discuss what they call the "disunity of science," and claim that there is no single "Science," but multiple sciences, with scientists from each science having their own sets of understandings[62] (this is paralleled by Deborah Gordon's argument that there is no single "biomedicine," but a range of local practices).[63] Galison states that the lack of unity between sciences means that if

[61] Fleck, op. cit., note 5.
[62] See for example Galison, P and Stump DJ (1996) (eds.) , *The Disunity of Science: Boundaries, Contexts and Power.* Stanford, CA: Stanford University Press.
[63] Gordon, op. cit., note 6.

scientists from different disciplines need or choose to work together, they create "trading zones" within which they develop common understandings.[64]

I have argued that the theory of total pain/care can be thought of as forming in a trading zone between several disciplinary communities; Cicely Saunders was trained as an almoner (equivalent to social worker), a nurse and a doctor, and so perhaps could be thought of as herself embodying a trading zone between three disciplinary communities (synthesising these perspectives, including her own, personal religious and/or spiritual beliefs and experiences, within herself), as well as contributing to a trading zone through her subsequent work with people from various disciplinary communities, a trading zone within which people eventually produced the specialty of palliative care.

I wondered, therefore, whether St Z's could be considered a "trading zone" between the various professions of the workers there: allopathic medicine, nursing, social work, occupational therapy, and physiotherapy. I thought that "trading" in St Z's would be most evident in case conferences, since these were situations in which workers most frequently interacted with each other as a collective. However, it seemed to me that in case conferences workers were not trying to achieve a single approach to care, nor seeking to synthesise their various disciplinary approaches. Instead, it seemed to me that workers in St Z's understood their roles as complementary. They shared common beliefs and understandings about health care which could be broadly summarised as "biopsychosocial," but, for them, each profession had its own area of responsibility, and workers worked alongside one another to contribute to the "total care" which they felt was delivered by the multi-disciplinary team as a whole. Case conferences reinforced and reproduced this sense of the complementarity of the division of labour between different professional groups.

It seems to me, therefore, at least in relation to my findings from St Z's, that the concepts of thought collective and trading zone are more relevant to the initial development of the modern hospice movement and palliative care than to the current

[64] Galison, op. cit., note 14.

practices of hospice workers. That is, these concepts seem to me to be more useful in relation to how people develop theories in the first place than to how people subsequently implement theories in practice. I therefore moved on to explore whether ideas from the field of "science as practice" offered anything of relevance to my findings.

Andrew Pickering and other theorists of science as practice argue that practices are not simply the extension of a "conceptual net," that is, are more complex processes than simply applying theories to the "real world," because when people try to apply their theories in practice they encounter "resistances," that is, anomalies and contradictions to their expectations.[65] Most workers in St Z's did not claim to apply the whole of the theory of total pain/care in their own individual practice, and for a while I wondered whether this was because they found it difficult to do so; whether they were encountering some kind of "resistance."

However, as noted, it seemed to me that most workers did not *expect* to apply the theory of total pain/care in its entirety in their own practice, especially in relation to its spiritual dimension. Although they claimed that total or holistic care was provided in St Z's, they did not feel that they, individually, did or should deliver total care. Instead, they considered that the various members of the multidisciplinary team addressed the various aspects of a patient's "total pain," so that each worker provided elements of total care in her/his particular role within the multidisciplinary team.

That is, it did not seem to me that workers in St Z's tried to implement the theory of total pain/care in practice, but failed because they encountered difficulties or resistances. Rather, they assumed that it *was* implemented in practice, although not by them personally, but by the multidisciplinary team as a whole. This was particularly striking in relation to the spiritual aspects of total care, which most workers felt were delivered by some other member of the multidisciplinary team, although they were vague as to who this other person was (and few could identify such a person when I specifically asked them if they could do so for me).

[65] Andrew Pickering (1992), 'From science as knowledge to science as practice,' pp. 1-26 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

So, it did not seem to me that the field of "science as practice" was helpful in relation to my findings. Through reflecting on the relevance (or lack of relevance) to my findings of this and the other social constructivist perspectives which I have outlined, I began to re-consider the concept of "paradigm," and to realise that I was not entirely clear what it meant. Next, therefore, as I discussed in chapter two, I returned to Kuhn and discovered his elaboration of the concept of "paradigm" (in its wider sense of "world view") into the more detailed, multi-dimensional concept of the "disciplinary matrix."[66] The disciplinary matrix comprises four elements: exemplars, symbolic generalisations, metaphysical models, and values, and I find this detail helpful.

Kuhn argued that people's judgments of which questions are important, and of which explanations and/or theories are credible, and of the appropriate actions to take in relation to these theories, shape and are shaped by their particular disciplinary matrix. He also argued that a new theory is incommensurable with an existing one, that is, that a person cannot simultaneously hold to both, and that merely understanding a new theory is not sufficient to take it fully on board, since to do so, one must reject the existing theory. A "conversion experience" is necessary for this to happen, and I have suggested that this is in part because for people to accept new theories they have to revise elements of their disciplinary matrices.

The elements of their disciplinary matrix which people most often need to change when they are converted to new theories are usually exemplars and/or symbolic generalisations, which are most directly theory-related. However, more far-reaching theories (such as the theory of total pain/care) may also challenge less explicit elements of disciplinary matrices, such as values and metaphysical models. While I accept the argument that there is no single "biomedicine" (or science), I think that some elements of disciplinary matrices, particularly values and metaphysical models, are not unique to the disciplinary matrix of a particular disciplinary community, but are shared with the disciplinary matrices of other disciplinary communities. David Bloor argues that people tend to conventionalise new concepts

[66] Kuhn, op. cit., note 2.

so that they fit with their existing understandings,[67] and I have suggested that this might be particularly the case when new concepts require people to revise their values or metaphysical models.

In relation to bodies of systematic knowledge concerning health and health care (which exist within and in interaction with the disciplinary matrices of the disciplinary communities of health care professionals), a person's metaphysical model for what people are – as an element of her/his disciplinary matrix – contributes to her/his understandings of health and (therefore) of health care.[68] The metaphysical model which is common to most of mainstream allopathic medicine constructs a person's body and mind as separate from each other (although possibly having an effect on one another) and a person's spirit (if it exists at all) as separate from both.[69] Professional health care within allopathic medicine is organised accordingly, such that different professional groups are responsible for one of these dimensions of a person, or sometimes for combinations of these dimensions. That is, the division of labour in allopathic medicine is grounded in this particular metaphysical model for what a person is – this division of labour only makes sense in relation to a metaphysical model which constructs people as made up of separate, and separable, parts.

I have argued that the spiritual dimension of the theory of total pain/care is key in distinguishing it from mainstream allopathic medical theories, since, because of this dimension, the theory relates, implicitly, to a profoundly different metaphysical model to that of much of allopathic medicine.[70] For the theory of total

---

[67] Bloor, op. cit., note 20.

[68] People may conceptualise people as only bodies, or as minds and bodies (separately or integrated), or as mind-body-spirit (again, as separate aspects or interwoven) – and health and health care mean different things according to the particular conceptualisation. See, for example, Henry T Dom (1999), 'Vaisnava Hindu and Ayurvedic approaches to caring for the dying,' *Innovations in End-of-Life Care,* 1 (6), www.edc.org/lastacts/archives/archivesNov99/intlpersp.asp

[69] This construction is evident in the egg and concentric circle models which I discussed earlier, and is perhaps also present to some extent in Twycross' 4S model, in which the dimensions of a person are separate, although overlapping.

[70] Without the spiritual dimension very little distinguishes total pain/care or hospice care or palliative care from allopathic medical specialties such as rehabilitation. See also David Field's comment that some definitions of palliative medicine describe good medical care of any patient with a chronic disease (Field (1994), 'Palliative medicine and the medicalization of death,' *European Journal of Cancer Care*, 3: 58-62: 61).

pain/care, a person's spirit is integral to their experiences of pain; pain is not solely physical or emotional (or indeed spiritual), but always multi-dimensional, with physical, psychological, emotional, social and spiritual dimensions. "Total care" for this pain entails attention to all these dimensions.

So the theory of total pain/care implies a metaphysical model whereby a person's mind, body and spirit are interwoven and inseparable, and is therefore incommensurable with most allopathic medical theories. This then implies that people who claim to accept this theory have either to reject existing theories or adapt ("conventionalise") the new one. In relation to my findings from my fieldwork, it seemed to me that most workers in St Z's seemed to understand holistic or total care within the framework of the division of labour associated with allopathic medicine, and the associated metaphysical model which separates a person's mind, body and spirit.[71] That is, it seemed to me that they conventionalised the theory of total pain/care within their existing understandings of health care and of their own, individual practices.

Workers in St Z's were aware of the philosophy of the modern hospice movement: the claim that hospice care integrates all aspects of care, and includes a spiritual dimension (which is distinct from religion). However, they conceptualised the spiritual part of a person as being elsewhere, separate from the other parts of a person, as in the metaphysical model of most of allopathic medicine, and, related to this, most workers conceptualised the spiritual aspects of care as distinct, elsewhere and/or separate from the other aspects of care, and often as not part of their own practice.

So, while workers generally claimed that practices in St Z's reflected a philosophy of holistic care, which included spiritual care, their individual practices varied and did not necessarily reflect the whole of this philosophy. That is, to use Argyris and Schön's terms,[72] workers in St Z's "espoused" the theory of total

[71] As with the tacit agreement amongst workers that death and dying and spirituality were not to be discussed in public, so too their non-explicit, taken-for-granted understandings of the division of labour and of the metaphysical models of allopathic medicine were also tacit, because taken-for-granted.

[72] Argyris and Schön, op. cit., note 3.

pain/care, but this was not the "theory-in-use" for most workers (and nor did they claim that it was). The practices of workers in St Z's, that is, seemed to me to relate less to the context in which they worked than to their professional backgrounds, that is, the disciplinary matrices of their immediate disciplinary communities (or thought collectives),[73] and also (because situated within) the wider disciplinary matrix common to most of allopathic medicine.

Nursing and the "professions allied to medicine" ("PAMs" – social work, occupational therapy, physiotherapy) are constructed in interaction with allopathic medicine and the associated division of labour (and, therefore, the fragmented metaphysical model of allopathic medicine). Different workers/professions are responsible for different parts of a person and a person's needs, and this division of labour is associated with a hierarchy of health care professionals, headed by allopathic medical doctors, who focus primarily on physical issues. Thus physical issues are effectively emphasised and prioritised (even if the importance of other issues is acknowledged), and effectively a hierarchy of care also exists, whereby the physical aspects of care are implicitly or explicitly identified as the most important aspects of care, since they are the main focus of doctors.[74]

The hierarchical organisation of health care associated with the multi-disciplinary team suggests that the person leading the multi-disciplinary team (and, to a lesser extent, leaders of teams within parts of the organisation, such as sisters on wards or the day care coordinator) has (have) a significant influence on the care which the multi-disciplinary team delivers; the leader models the philosophy of care. This was evident in St Z's, where Dr 5 was clearly the leader of the team, and, as

[73] As noted in chapter four, although workers in St Z's were in a sense working in palliative care, only Dr 21 had a specific palliative care background. Dr 5 (the medical director) had trained as an anaesthetist. The matron and deputy matron were both nuns, who had trained in other hospices (established prior to the modern hospice movement). The other nurses had been trained and/or practised in various situations; a few had come to St Z's immediately after completing their training. In contrast to the "first wave" of hospice workers in the early days of the modern hospice movement, few nurses in St Z's felt particularly "called" to care for the dying (and this was particularly the case for those who worked or had begun working on the elderly care ward, where workers did not consider themselves to be caring for dying people). Rather, many nurses thought of St Z's as a place where they could do "real nursing," the kind of nursing which they felt that they had been trained to do, and this was its appeal as a place of work.

noted, very much perceived his role as addressing physical issues, separately from other issues, which he identified as the responsibility of other members of the multi-disciplinary team.

Dr 5 led the case conferences and in these he focused mainly on physical issues, as he did also in his general approach to patients, where he addressed the physical aspects of pain first, via physical interventions such as nerve blocks, thus effectively separating the physical aspects of pain from its other aspects. Dr 5 was particularly reticent about spiritual issues, but during case conferences he did pay attention to emotional and social issues – it was noticeable that when he was not present at case conferences (at which times they were led by one of the GPs[75]), discussions focused predominantly on patients' physical health and associated needs, with little else discussed, unless other workers initiated such discussion (and this was seldom). However, Dr 5 did not perceive that his role was to address emotional and social issues. He highlighted the manner in which he perceived workers in St Z's delivered care ("TLC"), in contrast to "some brutal nurses out there," but allocated the responsibility for the non-physical aspects of care to nurses and PAMs.[76]

Nurses in St Z's also understood their areas of work and responsibility as distinct from, although complementing, those of doctors.[77] Many nurses in St Z's talked about "good nursing practice," and being able to do "real nursing" in St Z's. What most nurses in St Z's meant by "good nursing practice" or "real nursing," however, was "biopsychosocial."[78] For them, patients' minds and bodies were integrated, and their understanding of "holistic" or "total" care was broadly attending

[74] Jessica Corner (2003), 'The multidisciplinary team – fact or fiction?' *European Journal of Palliative Care*, 10 (2): 10-12.

[75] As I have discussed previously, Dr 21 began working at St Z's as I was coming to the end of my fieldwork, so I never attended a case conference where he was present. However, since, as noted, Dr 21's palliative care training in combination with his personal religious beliefs meant that he was interested in addressing patients' spiritual issues, his presence might well change the kinds of discussions which occur during case conferences.

[76] In contrast, it has been claimed that in St Christopher's hospice, Cicely Saunders' overt spiritual concern signals that it is acceptable, indeed, almost obligatory, for all workers, regardless of occupational role, to pay attention to the spiritual concerns of both patients and non-patients, in line with this charismatic, rule-breaking challenge to the dominant world view of allopathic medicine (James and Field, op. cit., note 11).

[77] Hence their discomfort when Dr 21 disrupted professional boundaries.

to physical needs with a caring attitude. This included attending to emotional and psychological needs, but for most nurses the spiritual component of holistic or total care was vague. This was also the case for PT 9, SW 10, and DCC 14 (who explicitly said that the spiritual aspects of care were not part of her job).

Thus, the overall organisation and allocation of work within St Z's reflected the metaphysical model of allopathic medicine, such that physical care was separate from other aspects of care, and came first, albeit with an emphasis on a "TLC"-type approach to delivering care. It seemed to me that the practices of workers in St Z's related more to this understanding than to their particular work environment, or to a philosophy of care which was specific either to St Z's or to hospices more widely. The importance of hospice for most workers was as an environment for good practice, not different practice.

For most workers in St Z's, therefore, the movement through the "levels" or "layers" (body-mind-spirit) of patients stopped at the mind and did not reach the spirit. However, individual workers with personal religious faith did seek to apply the whole of the theory of total pain/care, that is, sought to deliver care which had spiritual aspects. As a consequence, despite the statements of workers, and the stated policy of the hospice, that spirituality was distinct from religion, the spiritual aspects of care in St Z's were not entirely separate or distinct from the religious aspects.

This was not because carers imposed their religious beliefs on others,[79] but because those workers in St Z's who claimed to provide spiritual care (as distinct from having a sense of what spiritual care was) were all religious people who had a personal sense of spirituality. Linda Ross (née Waugh) also identified this as a characteristic of those nurses in her survey of nurses' perceptions of spiritual care

[78] See Andrew Oldnall (1996), 'A critical analysis of nursing: meeting the spiritual needs of patients,' *Journal of Advanced Nursing*, 23: 138-44.

[79] As I have said, they were very concerned *not* to do this, not only because of the rhetoric in hospices and palliative care generally which distinguishes between spirituality and religion, but also because St Z's was a Catholic hospice in a Protestant town in the West of Scotland, and this meant that people's religious affiliation was an issue. Although (or perhaps partly because?) the hospice was named after a saint, as were both wards, the nuns were extremely conscious of not inflicting their religious beliefs on other people.

who gave spiritual care on what she calls "a deep level,"[80] and she suggests that this is perhaps because such people, feeling that spirituality is important in their own lives, perceive that spiritual aspects of care are also important for patients.

Thus, only those workers who had religious beliefs claimed to provide care with spiritual aspects, and, since they were in a minority in St Z's, this meant that few workers provided such care. Further, those workers who did claim to provide such care had differing perceptions of what this involved, with some being more open to different understandings than others,[81] while some of those workers who felt that they did or should or wanted to provide spiritual care said that doing so was difficult, owing to the fear of "going deep," which, as noted, linked to issues of vulnerability.

This reticence also linked to questions of expertise, which were intimately interwoven with the division of labour amongst the members of the multi-disciplinary team. As noted, workers in St Z's perceived that the division of labour amongst a multi-disciplinary team which is common in most of the NHS also applied in St Z's, such that workers' professional roles, and the activities and responsibilities associated with these, were distinct from one another. Workers in St Z's felt that boundaries between professional roles were important, and associated these boundaries with particular sets of expertise, as evident in the strong sense of many workers that certain activities were "not my job."[82] This was especially notable in relation to the spiritual aspects of care, and seemed to me to be in part reflected in the absence of open discussion of spirituality amongst workers in St Z's.

This strong sense of having or lacking expertise relates to the increasing emphasis on training health care professionals (in particular, the professionalisation of nursing), and the distinction between "trained" and "untrained" staff, particularly nurses, was evident in St Z's. Yet, despite this increasing emphasis on training and education, and, as Anne Johnson points out, despite the increasing interest in spiritual

[80] Ross, op. cit., note 57; see also Linda Waugh (1992), 'Spiritual aspects of nursing: a descriptive study of nurses' perceptions,' unpublished PhD thesis, Queen Margaret College, Edinburgh.
[81] Thus Sr 13 was more open to various understandings, whereas Dr 21 was more convinced that his religious understanding was the (only) truth.
[82] As I discuss later in this chapter, the sense of not having expertise was/became powerful for me too.

care in nursing, spiritual care is seldom taught, and often only alongside religious and cultural needs, since many models of care used in nursing identify spiritual needs as an entity only in this context.[83] In relation to this, much of the nursing literature which discusses spiritual aspects of care argues that, although nurses are aware that spiritual care is increasingly said to be important, they do not feel competent to deliver such care. So, for example, Kristeller et al. state that significant numbers of cancer nurses feel that they should address patients' spiritual needs, but that they neglect these issues because of time constraints, their lack of confidence in managing these issues, and role uncertainty.[84]

Many publications in the nursing literature in recent years therefore seek to address this perceived problem, and one aspect of this is that the "nursing process" (assess, analyse, plan, intervene, evaluate) is increasingly applied to spiritual care.[85] Perhaps these divisions apply for some issues. So, for example, if a person mentions that they have religious concerns to a non-religious professional, that professional does not provide answers, but rather a referral to the appropriate religious professional. However, as Tony Walter argues, this rationalist process is incongruous when extended from physical to spiritual needs,[86] and I would amplify his point by suggesting that the nursing process perhaps does not, or cannot, apply to spiritual needs. If spiritual care involves actively engaging with patients' concerns, it seems to me that the distinction between assessing and intervening is not clear-cut. Nurses in St Z's seemed to me to be aware of this; perhaps they avoided engaging with patients' spiritual concerns ("assess") because they were uncertain of their ability to "intervene."

---

[83] Anne Johnson (1998), 'The notion of spiritual care in professional practice, pp. 151-66 in Cobb, M and Robshaw, V (eds.), *The Spiritual Challenge of Health Care*. Edinburgh and London: Churchill Livingstone: 152.

[84] Jean L Kristeller, Collette Sheedy Zumbrum and Robert F Schilling (1999), ''I would if I could': how oncologists and oncology nurses address spiritual distress in cancer patients,' *Psycho-Oncology*, 8 (5): 451-8. See also Elizabeth Johnston Taylor, Martha Highfield, and Madalon Amenta (1994), 'Attitudes and beliefs regarding spiritual care: a survey of cancer nurses,' *Cancer Nursing,* 17 (6): 479-87.

[85] Verna B Carson (1989), 'Spirituality and the nursing process,' pp. 150-79 in Carson, VB (ed.) *Spiritual Dimensions of Nursing Practice*. Philadelphia and London: WB Saunders: 155; Ross (1998), op. cit., note 57; Johnson, op. cit., note 81.

In addition, even if nurses were trained in providing spiritual care, whether or not that included the application of the nursing process, it is unclear what "expertise" would mean in relation to the spiritual aspects of care. It is difficult to know what it would mean for someone to be a "spiritual expert," since no one can really be an expert in an area which by definition deals with the unknowable. I suggest that spirituality is an area where the division of labour, both between workers and between workers and patients, breaks down – patients in St Z's often provided non-physical kinds of care for each other, and even for workers.[87]

Regina Milard argues that spiritual care 'entails entering into the vulnerability of listening and being, and of not necessarily having answers.'[88] If the "intervention" involves paying attention to the questions which someone is asking, not providing answers or solutions, then asking questions about spiritual concerns – "assessing" or "identifying" "spiritual need" – is the first step in any "intervention." I suggest, therefore, that doing research into spiritual care can come very close to providing spiritual care,[89] and I increasingly felt that my research could itself be close to

[86] Walter (1997), op. cit., note 48: 27. Also see Tony Walter (1994), *The Revival of Death.* London: Routledge, especially pp. 103-6.

[87] This also raises questions relating to the various critiques that claim that increasing parts of life are becoming medicalised (see, for example, David Armstrong (1986), 'The problem of the whole-person in holistic medicine,' *Holistic Medicine*, 1: 27-36 and (1987), 'Theoretical tensions in biopsychosocial medicine,' *Social Science and Medicine*, 25 (11): 1213-18), and the debate over whether health care professionals *should* address patients' spiritual needs (Field, op cit., note 75, and also Bronwen Biswas (1993), 'The medicalization of dying: a nurse's view,' pp. 132-9 in Clark D (ed.), *The Future for Palliative Care: Issues of Policy and Practice.* Buckingham: Open University Press). However, if health care professionals do not address these needs for people who would like support addressing them, it is debatable as to whether anybody else will. The increased focus on death and spirituality in the media in recent years (which, certainly for death, is of a particular sort: dramatic, if not violent, depictions tend to be the most frequent) does not necessarily reflect or translate into increased discussion of these issues in people's daily discourse (this has certainly not been my experience over the last several years researching spirituality and/or palliative care), and I suggest that if discussion of these issues is absent in a hospice it is unlikely to be present elsewhere.

[88] Milard, op. cit., note 47: 103. See also Cicely Saunders (1988), 'Spiritual pain,' *Journal of Palliative Medicine*, 4 (3): 29-32, and Gillian White (2000), 'An inquiry into the concepts of spirituality and spiritual care,' *International Journal of Palliative Nursing,* 6: 479-84.

[89] I suggest that it is also close to "person-centred counselling" (Dave Mearns and Brian Thorne (1999, 2nd edition), *Person-centred Counselling in Action*. London: Sage, and also Carl R Rogers (1951), *Client-centred Therapy: Its Current Practice, Implications and Theory*. London: Constable) in that the aim is to understand, not to judge or provide answers, although note Walter's concern that spiritual care might be reduced to a collection of technical skills, such as "communication skills" or "listening skills" (note 56 above). On expertise and "not knowing" in person-centred counselling see Liz Bondi with Judith Fewell (2003), '"Unlocking the cage door": the spatiality of counselling,' *Social and Cultural Geography*, 4: 527-547.

spiritual care, especially in a situation where few workers engaged with patients' "Why me?" questions.

Researching and/or providing spiritual care

As noted, those workers who claimed to provide care with spiritual aspects understood these in one of two ways, as either the manner or the content of the care which they gave. While I did not want nor set out to judge workers, through doing my fieldwork I, unavoidably, formed my own understandings of the spiritual aspects of care. I agreed with those few workers in St Z's who related the spiritual aspects of care to a particular content of care – actively engaging with patients' "Why me?" questions. Otherwise it does not seem to me that there is anything distinctive about hospice care or "total care." In terms of addressing spiritual concerns, being loving (expressive spiritual care) is only part of this – being loved may well be a spiritual need,[90] but it is not the only one (and also, if this is spiritual need, it is arguably indistinguishable from emotional or psychological need). I cared for patients and workers in St Z's, and felt loving towards some individuals, but I would not define this as spiritual care.

Thus, my perception was that the spiritual aspects of care were seldom present in St Z's, and, whether or not this perception was correct,[91] I felt that I had to act on this basis. I therefore did not interview patients about the spiritual aspects of care. My perception that the spiritual aspects of care were often absent developed over the course of my fieldwork, and early in my fieldwork, before I had come to this conclusion, I had arranged to interview a few patients who had initiated "Why me?" conversations with me. However, these people died or became unwell before we

[90] Martha Highfield and C Cason (1983), 'Spiritual needs of patients: are they recognized?' *Cancer Nursing*, 6 (3): 187-92.

[91] In the same way as workers in St Z's understood spirituality as not immediately evident, but beneath, beyond or behind other things, and therefore revealed last or necessitating "digging" for, so the spiritual aspects of care were not immediately evident to me either; I did not observe them, nor, even though I "dug" for them in interviews, did most workers say that they knew what they were. Of course, my difficulty with observing or eliciting descriptions of these aspects of care does not of itself mean that they were absent, since they could have occurred in private, when individual workers were with individual patients, and workers could have found it impossible to verbalise what they were. However, the difficulties which most workers found in identifying these aspects of care did suggest to me that it was unlikely that they occurred.

were able to do the interviews. Later, I was concerned that if I engaged patients in discussions about these aspects of care I would raise concerns for them, only to leave them alone with these concerns, since I could not be sure when I would next be able to pursue them further, nor was I sure whether any worker could or would do so. I felt that I would have been using patients for my benefit (that is, to contribute to my thesis) and leaving them uncared for. I therefore refrained from conducting in-depth taped interviews with patients.[92]

Alongside this, I felt that I was not qualified to accompany patients in exploring their spiritual concerns. That is, issues to do with expertise also arose for me, which resonated with workers' understandings of expertise and the division of labour. Perhaps I partly absorbed this sense of particular expertise, and what people were or were not "qualified" to do, from the prevalent attitude in St Z's. However, it was also the case that throughout my fieldwork I was conscious of having to perform the "researcher" role,[93] balancing knowing and not knowing – having to demonstrate that I "knew" things in order to be taken seriously, yet having to explore "the obvious" without appearing "stupid."[94] This tension was especially acute in relation to clinical issues.

Although my medical/scientific/technological background meant that I was familiar with the language used by workers, this was a double-edged sword, since, while workers therefore took me seriously, I found it difficult to look at situations with completely "new" eyes, or to ask "obvious" questions. In tandem with this, it also seemed to me important to flag up that I was *not* a health care professional. In relation to the spiritual aspects of care, therefore, there was a similarity between me and workers. I refrained from asking patients about spiritual issues, not only because

[92] Also see Bella Vivat (2002), 'Situated ethics and feminist ethnography in a West of Scotland hospice,' pp. 236-52 in Bondi, L et al., *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research.* Lanham, Maryland and Oxford: Rowman and Littlefield, appended as appendix VI.

[93] See Elizabeth H Young and Raymond H Lee (1996), 'Fieldworker feelings as data,' pp. 97-113 in James, V and Gabe, J (eds.), *Health and the Sociology of Emotions.* Oxford and Cambridge, MA: Blackwell, and Karen Ramsay (1996), 'Emotional labour and qualitative research: how I learned not to laugh or cry in the field,' in Lyon, ES and Busfield, J (eds.), *Methodological Imaginations.* London and Basingstoke: Macmillan.

of my feelings of responsibility towards the patients, but also because I felt that such questions were close to providing spiritual care, and I did not feel that this was my job, since I was not an expert, and it was not my role nor my responsibility.

This, of course, raises the general question of whether it is impossible to research absent aspects of care; in this particular case, whether it is only possible to investigate spiritual care in situations where it happens. I don't think that this is the case, but I do think that the investigator needs to be more prepared, having thought through the ethical issues which arise in such a situation, than I was at the beginning of my fieldwork. Towards the end of my fieldwork I had more confidence in this, and began to feel that any discussion of spiritual issues was perhaps better than none. However, I felt that by this time it was too late to interview any patients, not least because I would have felt the absence of those people who had died and who I had chosen *not* to interview. I also, again, had a complicated situated ethical sense that if I did so, I would have been interviewing these patients solely for my own benefit, to make my thesis seem more "complete." I felt more comfortable making this complex ethical choice explicit.

My perception that the spiritual aspects of care were largely absent in St Z's also raises questions concerning why I was given access to conduct my fieldwork there, which, as I discussed in chapter three, I gained very easily. It seems unlikely that the managers of any organisation (its "gatekeepers") would give access to someone to explore something which they felt was not there. Yet, as I mentioned above, PCC 24, a "pastoral care coordinator" (a priest/theologian), began work in St Z's as I was coming to the end of my fieldwork, shortly after Dr 21 had begun working there. PCC 24 identified his role as providing spiritual support for both patients and staff, and he discussed with me his perception that this was lacking in St Z's, and his plans to specifically train both workers and volunteers in this area.

The process of employing PCC 24 was under way before I began my fieldwork, which suggests that when the managers of St Z's gave me access they already perceived that the spiritual aspects of care were absent. Nevertheless,

[94] See Paul Atkinson on this point (1981; 2nd edition 1997), *The Clinical Experience: The*

although I interviewed and/or spoke frequently with various members of the management team, none of them ever said this to me, nor mentioned that they planned to employ PCC 24. Perhaps, however, they risked nothing by giving me access to do my fieldwork there. I would either state that spiritual care happened, or that it did not. If I reached the latter conclusion, the situation would have changed from that which I described with the arrival of PCC 24.

Reflections on my own production of knowledge

So, as I have indicated, I perceived that there was a gap between the theory of total pain/care which workers in St Z's "espoused" and their practices, or theories "in-use."[95] As I worked on this study I also became increasingly aware of a similar gap between theory and practice for myself, and of the difficulty of implementing radically different theories in practice. My interest in spirituality and the spiritual aspects of care developed from my interest in excluded knowledges, and the project of feminists, including feminist theorists of knowledge, to find ways of validating and making visible those issues which are not generally taken as part of knowledge; asking those questions which are often not asked, such as questions about the work which women do and about things which are not measurable or quantifiable. Harding argues that systematic knowledge and systematic ignorance are necessarily produced simultaneously – the questions which are asked imply other questions which are not.[96] Spirituality is an area which is often ignored by allopathic medicine, and by social science, and questions are frequently not asked about spirituality, in part because the ways in which people in these disciplines often ask questions do not fit with spirituality. Thus, as I have discussed, there seemed to me to be a parallel between my theoretical approach and what I sought to study.

I therefore began this project intending to apply engaged social constructivist theories of knowledge to my own practice. My fieldwork was grounded in engaged social constructivism and I used a feminist ethnographic approach – two linked

Construction and Reconstruction of Medical Reality. Aldershot and Brookfield, Vermont: Ashgate).

[95] Argyris and Schön, op. cit., note 3.

[96] Sandra Harding (1998), *Is Science Multicultural? Postcolonialisms, Feminisms and Epistemologies*. Bloomington, Ind: Indiana University Press.

positions which both emphasise representing the hitherto unrepresented – and I set out to adopt a position of "connected detachment," since, as Harding argues, complete detachment is impossible, yet a degree of detachment is necessary for "strong objectivity."[97] I was aiming to be concerned and involved, yet not to become fully absorbed and so uncritical.

However, my findings were strongly of absence, not presence: absence both of general talk about the spiritual aspects of care and of specific claims by most workers that they delivered such care. As a result of these latter absences, another absence is also apparent in my thesis: the absence of patients' voices on the subject of the spiritual aspects of care. An additional absence which is present for me is the sense of my own absence from St Z's after I had completed my fieldwork; an absence which, as I discussed in chapter three, I found very difficult. The challenge of my thesis, therefore, became not the challenge which I anticipated when I began: that of how to describe the intangible (the spiritual aspects of care). Instead, the challenge became one of how to discuss these multiple absences, and, in particular, my perception that the spiritual aspects of care were absent in St Z's, and my attempt to understand why they were absent.

These multiple absences meant that when I came to write, I found writing extremely difficult. Paralleling the difficulty which the people I interviewed had with talking about the spiritual aspects of care, I struggled to write about what was absent and not apparent; I found it difficult to write about what workers did not say or struggled to say. Even before I began the study I felt that writing about spirituality might well miss the point (since, as noted above, spirituality is something which can only ever be written "about," in the literal sense of around; circling, not engaging with). This seemed to be also, perhaps even more, the case in writing about the *absence* of spiritual aspects of care.

Further, writing about this absence also raised questions for me about how to write constructively about something which could potentially appear a criticism. I liked many of the people in St Z's, and missed them after ending my fieldwork. I felt

[97] Sandra Harding (1991), *Whose Science? Whose Knowledge?* Milton Keynes: Open University

strongly that writing about my fieldwork was necessarily limited, involving a reduction and simplification of the complexity in St Z's. This, while unavoidable, nevertheless seemed to me to do a disservice to the workers, and even potentially to be damaging to them, and I found this extremely difficult. I worked hard to highlight the partiality and historical specificity of my findings.

I also found the linearity of a written thesis problematic when trying both to convey the multiple perspectives of people in St Z's and also to interweave theory and empirical findings. When I first began thinking about writing I had ambitious plans to represent my findings in a way which would indicate the limitations of writing, in particular, my dissatisfaction with the linear form. I considered various ways of doing this, such as using CDs with hyperlinks or attempting to reproduce a hyperlink-type structure on paper, such that I would indicate points of connection between different parts of the same chapter and between different chapters. However, I found it difficult to sustain these ambitious creative approaches and to feel that they would be taken seriously as a piece of academic work. I also found writing very slow, both for the above reasons and because of my (consequent) frustration with the end result. It took me a long time to write anything at all that I was satisfied with, let alone anything too unusual or complex, so I eventually abandoned the attempt to find a novel way of writing.

The context in which I was writing also contained multiple perspectives; my approach was strongly cross-disciplinary, drawing on science studies, ethnography, nursing and human geography. At the outset I also had ambitions to synthesise approaches from these various fields, but found it very difficult to do this while also identifying or keeping focused on a single argument. Eventually, therefore, I returned to the field of social construction of knowledge, a single perspective (although with various positions within the field), which seemed to me to be manageable, and which was also the source of my original interest. Ultimately, too, I returned to one of the original theorists in this field: Thomas Kuhn, whose work seemed to me more relevant to my findings than subsequent developments in the

Press.

field. Thus, after exploring various approaches, I returned to where I had started, albeit with a new perspective.

I encountered a further difficulty in attempting to write about two things in parallel, that is, about theory and practice on two levels: my findings in St Z's in relation to the spiritual aspects of care, and also my reflexive reflections on my own theory and practice. Since questions of and for theory are central to my thesis, I wanted to indicate the various theoretical approaches which I explored while developing my framing theory, rather than following the usual convention for theses whereby the development of theory is "written out" and, *post hoc*, constructed as a rational, linear process. I wanted to accurately represent what was involved in the development of my theoretical understanding; as part of situating my own knowledge I wanted to trace this process; and my movement through various social constructivist positions. Again, though, I found this complex, slow and time-consuming.

In addition, my framing approach and starting point, engaged social constructivism, began to seem insufficiently concrete to me. I sought not only to indicate who I was (and so identify the factors which shape my own production of knowledge), through autobiography, but also to "situate" my knowledge by demonstrating how I produced this knowledge in interactions with people in fieldwork site, and through my sense of responsibility for and empathy with them. However, I began to be unsure about how engaged social constructivism applied to how I wrote my thesis. This approach began to seem to me more relevant to the process of doing my fieldwork than to writing about it.[98] It seemed to me that taking a particular approach to the way in which I produced knowledge did not necessarily mean that I was producing knowledge with a particular content. I wondered what else was involved beyond situating my knowledge by framing it autobiographically, and writing in a more engaged style than the usual detached academic writing. The

[98] There is an interesting parallel here with my sense that the approaches of theorists of the "disunity of science" or "science as practice" are more relevant to theorising the development of theories than to theorising the practices of workers in St Z's.

question of content seemed more challenging than this (and this, interestingly, parallels the distinction I have made between the manner and the content of care).

Thus, I struggled to implement the theory of social constructivism in the written part of my production of knowledge. It seemed to me that it was one thing to apply this theory to my fieldwork practice, that is, to be an engaged researcher in "the field," being conscious of co-constructing my findings with people in the fieldwork site, but quite another thing to apply this theory of engagement to my production of knowledge in written form.

CONCLUSIONS

As noted, this has been a story of absences, and there are many absences in this thesis. One key absence is that of patients' voices, so my thesis focuses primarily on workers' perceptions. Thus, workers' lack of talk with patients around death and spirituality is paralleled in my thesis. This is an obvious place where further research, exploring patients' perceptions of spiritual care, would clearly be valuable. Other research possibilities, relating to absences (that is, to issues which I did not address and paths which I did not follow during my fieldwork, but became aware of later) include:

A more detailed, and specific, exploration of people's use of metaphors, particularly investigating metaphors which people use for spirituality and for death; examining the use of "getting deeper," and how workers and patients reached the conclusion that someone was "going down" (particularly when this was said for a relatively long time, as it was about Jimmy M).

Linking to this, it would also be interesting to investigate more specifically how workers evaluated some patients' deaths as "good" and some patients and their families as having "done well" (as I discussed briefly in chapter four), and the associated interweaving between care and control, in relation to the "good death." I also indicated in chapter four that workers and patients seemed to attach different meanings to "hope" and "awareness" of terminal diagnosis, and a more detailed examination of the meanings of these concepts would also be worthwhile.

A third issue which I think would repay further exploration is the question of expertise, and how health care workers, especially in multi-disciplinary teams, identify what is "my job" and what is "not my job," but someone else's.

Building from my thesis, another interesting study would be an ethnography of St Z's as it is now, subsequent to the significant changes which occurred towards the end of my fieldwork, with the wards having changed round, and the employing of two key new workers (in relation to the spiritual aspects of care): Dr 21 and PCC 24.

It would also be interesting to study the practices of other communities which claim to provide health care based on philosophies of health and health care which explicitly include a spiritual dimension. Through my reflections on my fieldwork I have become particularly interested in Ayurvedic medicine, which conceptualises health as a person being "in balance."[99] A person's spirituality is explicitly conceptualised as part of this balance, and ill health is the result of an imbalance.[100] This understanding of health and health care reflects a different disciplinary matrix, which includes a profoundly different metaphysical model (relating to Hindu philosophy), from that of allopathic medicine. Thus, a study of an Ayurvedic community caring for people with chronic and/or terminal illnesses would be an interesting complement to this one.

Having considered the possible developments of this study, I will now return to summarise and conclude the particular story of absences which I have told. As I have discussed, before I began my fieldwork I expected that the problems I would encounter would relate to trying to represent something which was less explicit than problem-focused/solving care; I anticipated difficulties with representing the intangible aspects of care. However, the story instead became one of understanding the absence of the particular aspect of care in which I was interested; understanding why spiritual care did not happen in any consistent way; why few workers claimed or expected to deliver such care; and the various understandings of the spiritual aspects of care of those workers who *did* claim to deliver care which had such aspects.

[99] Dom, op. cit., note 66.
[100] That is, rather than the actions of an external physical agent, such as an infectious agent, as in allopathic medical understandings.

I initially set out to look at the relation between the theory of total pain/care and the practices of workers in a particular hospice (St Z's), with a particular focus on the spiritual aspects of care, and I was concerned not to fragment a kind of care which claimed to be holistic. However, it seemed to me that the particular "whole" which is conceptualised in the theory of total pain/care did not really exist in St Z's.

Workers in St Z's seemed to me to deliver very high quality, individualised care. However, neither in the perceptions of most workers, nor in mine, were practices in St Z's distinct from "good practice" or "biopsychosocial care" elsewhere. Most workers tended to avoid "difficult" issues such as talk about death and its meaning, and few workers considered that they personally did or should deliver spiritual care. The only *collective* understanding of the spiritual aspects of care in St Z's was that they were not part of daily practice.

Thus, although workers in St Z's were aware of the philosophy of holistic or total care, they did not necessarily identify it as having any consequences for their *individual* practices. Instead, they divided the "whole" of total care into its "parts," along the lines of the division of labour of mainstream allopathic medicine. This was especially evident in relation to the spiritual "part," which, since it was separated, could therefore be absent.

Practices differed between workers in the various parts of St Z's, both as individuals and also in relation to their professional roles. St Z's was multi-disciplinary rather than inter-disciplinary,[101] and workers perceived that "holistic," or "total care" was provided by the multi-disciplinary team, that is, that total care was the outcome of all the actions of all the members of the multi-disciplinary team. Because of this, and because practices varied between workers and across St Z's, gaps in the "totality" of total care were possible.

These gaps were particularly significant in relation to the spiritual aspects of care. Although many workers stated that the spiritual aspects of care were important, most workers were extremely uncertain about what these aspects of care involved, and (therefore) whose responsibilities these aspects of care were. For most workers

the spiritual aspects of care were elsewhere: down, deep, or in someone else's job description, and indeed, these aspects of care were *not* part of anyone's job description. Only a few workers identified these aspects of care as part of their own practice, and they had differing understandings of what this involved.

Of these few workers, one (SN 2) had an expressive understanding of the spiritual aspects of care; to her, this related to the manner in which she provided all the care which she gave. However, I find it difficult to see what, in this case, would distinguish the spiritual aspects of care from emotional or psychological. The other workers in this small group (Sr 13, SN 16, SN 17, and Dr 21) defined the spiritual aspects of care as more instrumental, relating to a particular content: "going deeper" with the patient. About half these workers found talking about such care difficult, and there were no structures for its provision, unlike, for example, the emotional aspects of care (which were already, explicitly, part of the "nursing process").

Nicky James and David Field have argued that the modern hospice movement can be understood in the light of Weber's theory of charismatic movements, and his claim that as such movements become more successful and increase in size, so they become bureaucratised, and the initial radicalism is diluted.[102] With increasing bureaucratisation comes increasing hierarchy, rule-bound behaviour, and division of labour, with associated specialisations.[103] James and Field claim that early modern hospices left the mainstream because forces militated against the development of the model of care which pioneers of the modern hospice movement wished to promote, and James and Field asked (in 1992) whether the bio-medical emphasis of mainstream medicine would affect the categories of care which hospices emphasise, and whether physical issues would be prioritised.[104]

---

[101] In contrast to the trading zone where palliative care developed, and the early days of the modern hospice movement (Corner, op. cit., note 73).
[102] James and Field, op. cit., note 11: 1365.
[103] James and Field, op. cit., note 11: 1369.
[104] James and Field, op. cit., note 11: 1370. Concern is also increasingly expressed within palliative care that practitioners of palliative care could become just "symptomatologists," and so lose what makes palliative care distinct (Michael Kearney (1992), 'Palliative medicine: just another specialty?', *Palliative Medicine*, 6: 39-46).

I did feel that this was the situation in St Z's, where I conducted my fieldwork in 1998, and I suggest that one of the forces which seemed to be militating against total pain/care in St Z's was the disciplinary matrix of allopathic medicine, especially its metaphysical model, and the associated division of labour. I have suggested that the theory of total pain/care is incommensurable with the mainstream metaphysical model of allopathic medicine, and that, for a range of reasons (including the model of care presented by the medical director (Dr 5) and the perceptions of some workers of a lack of support from managers), most workers in St Z's conventionalised the theory of total pain/care, such that they excluded its spiritual aspect. That is, I suggest that my findings illustrate how people conventionalise a radical theory to fit with their disciplinary matrices, including their metaphysical models, rather than the routinisation of care which James and Field suggested might be a consequence of the assimilation of hospices into the allopathic medical mainstream.

The underpinning metaphysical model of allopathic medicine separates body, mind and spirit, and this metaphysical model produces and reproduces the division of labour in most of allopathic medicine. In this division of labour amongst the members of the multi-disciplinary team, the whole of care is identified as the sum of its parts; the various activities of the members of the multi-disciplinary team. I suggest that workers in St Z's perceived the theory of total pain/care through the prism of their NHS (allopathic medical) training, and so they absorbed or conventionalised the radical theory of total pain/care in terms of the allopathic medical model.

Part of my initial interest when I began this study was in whether change is possible from within or without. The pioneers of the modern hospice movement moved out of the mainstream in order to influence it, and on one level this could be said to have happened, since modern hospices are now established organisations, in the UK and internationally, and palliative care has been an allopathic medical specialty for the last twenty years. However, as the modern hospice movement moved back towards the mainstream, so a new "trading zone" could be considered to have developed.

In this trading zone, people from within palliative care talk with people from other allopathic medical specialties, who share the elements (values and metaphysical models) which are common to the disciplinary matrices of much of allopathic medicine. Each party in a trading zone influences the other (and this influence is reciprocal, both creative and disruptive). So palliative care affects and is affected by allopathic medicine more widely. Communication between these different groups requires translation, which perhaps in turn requires simplification and, therefore, loss of subtleties. In turn, this may result in increasing conventionalisation of the theory of total pain/care. If St Z's is not anomalous, my findings suggest that, through its absorption into mainstream allopathic medicine, the modern hospice movement has been diluted, via the conventionalisation of the radical theory which underpins it.

It is interesting to compare the different responses to the theories of social constructivism and of total pain/care. Both these theories challenge existing theories on a profound level, but the responses to them have been markedly different. Social constructivism has met with considerable resistance and antagonism from within both the natural science community and orthodox history and philosophy of science. Conversely, the theory of total pain/care has not met with such extreme reaction; indeed, a new allopathic medical specialty developed from the modern hospice movement. Perhaps this was because of the deliberate strategy of working from the outside to effect change. Alternatively, it is possible that the allopathic medical community does not – or chooses not to – recognise how profoundly challenging this theory is, perhaps because it can be partially aligned with moves towards the "biopsychosocial" and to "re-humanise" allopathic medicine.[105]

In recent years, in association with the increasing interest in spiritual issues within health care, there has been an increasing emphasis on spiritual care in policy and (related to this) in nursing and other health care literature.[106] In Scotland in

[105] Armstrong, op. cit., note 86.

[106] See for example Johnson, op. cit., note 81; Institute of Nursing, University of Leeds, National Health Service Executive, Northern Yorkshire (1995), *A Framework for Spiritual Faith and Related Pastoral Care.* Manchester: Barkers; and National Association of Health Authorities and Trusts (1996), *Spiritual Care in the NHS: A Guide for Purchasers and Providers.* Birmingham: National Association of Health Authorities and Trusts. Associated with this increased attention to the spiritual aspects of care has come an increased interest in measuring spirituality (again, seeking to fit this

particular, the Scottish Executive Health Department published Guidelines for spiritual care in 2002.[107] This concern for spiritual issues does not only relate to care at the end of life, but throughout health care. Yet, in St Z's, an organisation which provides care for dying people, and so where one might expect to find spiritual aspects of care, I found identifying how these aspects of care were provided problematic. I suggest that if policy dictates do not take account of the fundamental metaphysical model of allopathic medicine and associated division of labour, which often effectively equate "holistic care" with "biopsychosocial" care, health care workers will continue to conventionalise the spiritual aspects of care within their existing understandings, such that these aspects of care are located elsewhere, and/or as part of someone else's job.

approach into the rationalist discourse of allopathic medicine) (Wilfred McSherry and Linda Ross (2002), 'Dilemmas of spiritual assessment: considerations for nursing practice,' *Journal of Advanced Nursing*, 38(5): 479-88). This interest in measuring and rationally accounting for spirituality contrasts with Saunders' claim that the spiritual aspects of total pain exist, regardless of whether or not it is possible to measure them.

[107] Scottish Executive Health Department (2002), 'Guidelines on chaplaincy and spiritual care in the NHS in Scotland.' Edinburgh: NHSScotland.

BIBLIOGRAPHY

A

Abu-Lughod, Lila (1991), 'Writing against culture', pp. 137-62 in Fox, RG (ed.), *Recapturing Anthropology: Working in the Present*. Santa Fe: School of American Research Press.

Acheson, Donald (1998), *Inequalities in Health: An Independent Inquiry into Inequalities in Health; a Report.* London: Stationery Office.

Adler, PA and Adler P (1994), 'Observational techniques,' pp. 377-92 in Denzin, NK and YS Lincoln (eds.), *Handbook of Qualitative Research*. Sage, London.

Agar, Michael H (1986), *Speaking of Ethnography.* Beverley Hills, London, New Delhi: Sage.

Agar, Michael H (1980), *The Professional Stranger: An Informal Introduction to Ethnography*. New York and London: Academic Press.

Alvares, Claude (1988), 'Science, colonialism and violence: a Luddite view,' pp. 68-112 in Nandy, A (ed.), *Science, Hegemony and Violence: A Requiem for Modernity.* New Delhi and Oxford: Oxford University Press.

Amit, Vered (2000), 'Introduction: constructing the field,' pp. 1-18 in Amit, V (ed.) *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

Amit, Vered (ed.) (2000), *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

Anderson, Michael (2001), ''You have to get inside the person' or making grief private: image and metaphor in the therapeutic reconstruction of bereavement,' pp. 135-43 in Hockey, J, Katz, J and N Small (eds.), *Grief, Mourning and Death Ritual.* Buckingham: Open University Press.

Argyris, Chris and Donald A Schön (1974), *Theory in Practice*. San Francisco: Jossey-Bass.

Armstrong, David (1987), 'Theoretical tensions in biopsychosocial medicine,' *Social Science and Medicine*, 25 (11): 1213-18.

Armstrong, David (1986), 'The problem of the whole-person in holistic medicine,' *Holistic Medicine*, 1: 27-36.

Armstrong, David (1983), *Political Anatomy of the Body: Medical Knowledge in Britain in the Twentieth Century*. Cambridge: Cambridge University Press.

Ashmore, Malcolm (1990), *The Reflexive Thesis*. London and Chicago: University of Chicago Press.

Atkinson, Paul (1981; 2nd edition 1997), *The Clinical Experience: The Construction and Reconstruction of Medical Reality*. Aldershot and Brookfield, Vermont: Ashgate.

B

Baier, Annette (1985/1993), 'What do women want in a moral theory?' pp. 19-32 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Baier, Annette C (1991), 'Whom can women trust?' pp. 233-45 in Card, C (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Bajaj, Jatinder K (1988), 'Francis Bacon, the first philosopher of modern science: a non-Western view,' pp. 24-67 in Nandy, A (ed.), *Science, Hegemony and Violence: A Requiem for Modernity.* New Delhi and Oxford: Oxford University Press.

Bar On, Bat-Ami (1991), 'Why terrorism is morally problematic,' pp. 107-25 in Card, Claudia (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Bardige, Betty, Ward, Janie Victoria, Gilligan, Carol, Taylor, Jill McLean and Gina Cohen (1988), 'Moral concerns and considerations of urban youth,' in Gilligan, C, et al. (eds.), *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education.* Cambridge, MA and London: Harvard University Press.

Barnard, David, Towers, Anna, Boston, Patricia and Yanna Lambrinidou (2000), *Crossing Over: Narratives of Palliative Care*. Oxford and New York: Oxford University Press.

Barnes, Barry (1974), *Scientific Knowledge and Sociological Theory*. London: Routledge and Kegan Paul.

Barnes, Barry and David Bloor (1982), 'Relativism, rationalism and the sociology of knowledge,' pp. 21-47 in Hollis, M and S Lukes (eds.), *Rationality and Relativism*. Oxford: Blackwell.

Barnes, Barry, Bloor, David and John Henry (1996), *Scientific Knowledge: A Sociological Analysis.* London: Athlone and Chicago: Chicago University Press.

Bartlett, Frederic C (1932), *Remembering: A Study in Experimental and Social Psychology.* Cambridge: Cambridge University Press.

Becker, Howard S (1986), *Writing for Social Scientists: How to Start and Finish your Thesis, Book, or Article.* Chicago and London: University of Chicago Press.

Becker, Howard S, Geer, Blanche, Hughes, Everett C, and Anselm L Strauss (1961/76), *Boys in White: Student Culture in Medical School.* Chicago: University of Chicago Press.

Behar, Ruth (1995), 'Introduction: out of exile,' pp. 1-29 in Behar, R and D Gordon (eds.), *Women Writing Culture.* Berkeley, Los Angeles, London: University of California Press.

Behar, Ruth and Deborah Gordon (eds.) (1995), *Women Writing Culture.* Berkeley, Los Angeles, London: University of California Press.

Belenky, Mary, Clinchy, Blythe, Tarule, Jill and Nancy Rule Goldberger (1986), *Women's Ways of Knowing.* New York: Basic Books.

Bell, Diane and Renate Klein (eds.) (1996), *Radically Speaking: Feminism Reclaimed.* London: Zed Books.

Bell, Diane (1993), 'Introduction 1: The context,' pp. 1-18 in Bell, D, Caplan, P, and WJ Karim (1993) (eds.), *Gendered Fields: Women, Men and Ethnography.* London: Routledge.

Bell, Diane, Caplan, Pat and Wazir Jahan Karim (1993) (eds.), *Gendered Fields: Women, Men and Ethnography.* London: Routledge.

Bellert JL (1989), 'Humor: a therapeutic approach to oncology nursing,' *Cancer Nursing*, 12 (2): 65-70.

Bendelow, Gillian (1993), 'Using visual imagery to explore gendered notions of pain,' pp. 212-28 in Renzetti, CM and RM Lee (eds.), *Researching Sensitive Topics.* Newbury Park, London, New Delhi: Sage.

Benhabib, Seyla (1987/1992), 'The generalized and the concrete other,' pp. 267-300 in Frazer, E, Hornsby, J and S Lovibond (eds.), *Ethics: A Feminist Reader.* Oxford and Cambridge, US: Blackwell.

Benner, Patricia (1984), *From Novice to Expert: Excellence and Power in Clinical Nursing Practice.* Menlo Park, California: Addison-Wesley.

Benner, Patricia and Judith Wrubel (1989), *The Primacy of Caring: Stress and Coping in Health and Illness.* Menlo Park, California: Addison-Wesley.

Berger, Peter Ludwig and Thomas Luckmann (1967), *The Social Construction of Reality: A Treatise in the Sociology of Knowledge.* Harmondsworth: Penguin.

Biagioli, Mario (1996), 'From relativism to contingentism,' pp. 189-206 in Galison, P and Stump DJ (eds.), *The Disunity of Science: Boundaries, Contexts and Power.* Stanford, CA: Stanford University Press.

Bishop, Anne H and John R Scudder (1991), *Nursing: The Practice of Caring.* New York: National League for Nursing Press.

Biswas, Bronwen (1993), 'Medicalization of dying: A nurse's view', pp. 132-9 in Clark, D (ed.), *The Future for Palliative Care: Issues of Policy and Practice.* Buckingham and Bristol, PA: Open University Press.

Black, Douglas (1982; edited by Peter Townsend and Nick Davidson), *Inequalities in Health: The Black Report.* Harmondsworth: Penguin.

Blackmore, Susan (1993), *Dying to Live: Science and the Near-Death Experience.* London: HarperCollins.

Bloor, David (forthcoming), 'The sociology of scientific knowledge,' in Niiniluoto, I, Sintonen, M and J Wolenski (eds), *Handbook of Epistemology.* Dordrecht: Kluwer Press.

Bloor, David (1997), 'Remember the strong programme?' *Science, Technology and Human Values*, 22: 373-85.

Bloor, David (1992), 'Left and right Wittgensteinians,' pp. 266-82 in Pickering, A (ed.), *Science as Practice and Culture.* Chicago and London: University of Chicago Press.

Bloor, David (1976; 2nd edition 1991), *Knowledge and Social Imagery.* Chicago: University of Chicago Press.

Blum, Lawrence (1994), 'Vocation, friendship and community: limitations of the personal-impersonal framework,' in *Moral Perception and Particularity.* Cambridge: Cambridge University Press.

Blum, Lawrence (1988), 'Gilligan and Kohlberg: implications for moral theory,' *Ethics* 98: 472-91.

Blumer, Herbert (1969), *Symbolic Interactionism: Perspective and Method.* Englewood Cliffs, NJ: Prentice-Hall Inc.

Bock, Gisela, and Susan James (eds.) (1992), *Beyond Equality and Difference: Citizenship, Feminist Politics and Female Subjectivity.* London and New York: Routledge.

Bondi, L, Avis, H, Bankey, R, Bingley, A, Davidson, J, Duffy, R, Einagel, VI, Green, A-M, Johnston, L, Lilley, S, Listerborn, C, McEwan, S, Marshy, M, O'Connor, N, Rose, G, Vivat, B and N Wood (2002), *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research*. Lanham, Maryland and Oxford: Rowman and Littlefield.

Bondi, Liz with Fewell, Judith, (2003), '"Unlocking the cage door": the spatiality of counselling,' *Social and Cultural Geography,* 4: 527-547.

Bondi, Liz (1997), 'In whose words? On gender identities, knowledge and writing practices', *Transactions of the Institute of British Geographers*, 22: 245-58.

Bookchin, Murray (1989), *Remaking Society*. Montreal: Black Rose Books.

Booth, K, Maguire, PM, Butterworth, T and VF Hillier (1996), 'Perceived professional support and the use of blocking behaviours by hospice nurses,' *Journal of Advanced Nursing*, 24 (3): 522-7.

Borges, Jorge Luis (1993, translated by Ruth LC Simms) *Other Inquisitions 1937-1952.* Austin, Texas: University of Texas Press.

Bottorroff, J, Gogag, M and Engleberg-Lotzkar, M (1995), 'Comforting: exploring the work of cancer nurses,' *Journal of Advanced Nursing*, 22: 1077-84.

Bourdieu, Pierre (1977, translated by Richard Nice), *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.

Bowden, Peta (1997), *Caring: Gender-Sensitive Ethics.* London and New York: Routledge.

Bowen, Elenore Smith (1954/1964), *Return to Laughter.* New York and London: Doubleday.

Bowles, Gloria (1983), 'Is women's studies an academic discipline?' pp. 32-45 in Bowles, G and RD Klein (eds.), *Theories of Women's Studies*. London: Routledge and Kegan Paul.

Bowles, Gloria and Renate D Klein (1983), 'Introduction: theories of women's studies and the autonomy/integration debate', pp. 1-26 in Bowles, G and RD Klein (eds), *Theories of Women's Studies*. London: Routledge and Kegan Paul.

Braidotti, Rosi (1992), 'On the female feminist subject, or: from 'she-self' to 'she-other',' in Bock, G and S James (eds.), *Beyond Equality and Difference: Citizenship, Feminist Politics and Female Subjectivity*. London and New York: Routledge.

Brandt, Willy (chair, The Independent Commission on International Development Issues) (1980), *North-South: A Programme for Survival: Report of the Independent Commission on International Development Issues*. London: Pan.

Broadbent, Donald (1973), *In Defence of Empirical Psychology*. London: Methuen.

Broughton, John M (1983/1993), 'Women's rationality and men's virtues: a critique of gender dualism in Gilligan's theory of moral development,' pp. 112-39 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Brown, Lyn Mikel and Carol Gilligan (1992) *Meeting at the Crossroads: Women's Psychology and Girls' Development*. Cambridge, MA and London: Harvard University Press.

Buchwald, Jed Z (ed.) (1995), *Scientific Practice: Theories and Stories of Doing Physics*. Chicago and London: University of Chicago Press.

Bulmer, Martin (1986), *Social Science and Social Policy*. London: Allen and Unwin.

Butler, Judith (1990), *Gender Trouble: Feminism and the Subversion of Identity.* New York and London: Routledge.

Byrne, Marjory (2002), 'Spirituality in palliative care: what language do we need?' *International Journal of Palliative Nursing*, 8 (2): 67-74.

C

Callahan, Daniel (1995), *Setting Limits: Medical Goals in an Aging Society*. London: Simon and Schuster.

Callebaut, Werner (1995), *Taking the Naturalistic Turn or How Real Philosophy of Science is Done: Conversations with William Bechtel et al*. Chicago and London: University of Chicago Press.

Callon, Michel and Bruno Latour (1992), 'Don't throw the baby out with the Bath school! A reply to Collins and Yearley,' pp. 343-68 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Cameron, Deborah (1998), 'Gender and language: gender, language, and discourse: a review essay', *Signs: Journal of Women in Culture and Society,* 23 (4): 945-973.

Campbell, Alan Tormaid (1989), *To Square With Genesis: Causal Statements and Shamanic Ideas in Wayãpí*. Edinburgh: Polygon.

Cannon, Katie (1988), *Black Womanist Ethics.* Atlanta: Scholars Press.

Caputo, Virginia (2000), 'At 'home' and 'away': reconfiguring the field for late twentieth-century anthropology,' pp. 19-31 in Amit, V (ed.) *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

Card, Claudia (1991) (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Card, Claudia (1991), 'The feistiness of feminism,' pp. 3-31 in Card, C (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Carnap, Rudolf (1952), *The Continuum of Inductive Methods.* Chicago: University of Chicago Press.

Carson, Verna B (1989), 'Spirituality and the nursing process,' pp. 150-79 in Carson, VB (ed.) *Spiritual Dimensions of Nursing Practice*. Philadelphia and London: WB Saunders.

Carson, Verna B (1989) (ed.), *Spiritual Dimensions of Nursing Practice*. Philadelphia and London: WB Saunders.

Cavarero, Adriana (1992), 'Equality and sexual difference: amnesia in political thought', in Bock, G and S James (eds.), *Beyond Equality and Difference: Citizenship, Feminist Politics and Female Subjectivity*. London and New York: Routledge.

Chodorow, Nancy J (1978), *The Reproduction of Mothering: Psychoanalysis and the Sociology of Gender*. Berkeley: University of California Press.

Church, Kathryn (1995), *Forbidden Narratives: Critical Autobiography as Social Science*. Luxembourg: Gordon and Breach Publishers.

Clark, David (1993) (ed.), *The Future for Palliative Care: Issues of Policy and Practice*. Buckingham: Open University Press.

Clark, David (1993) (ed.), *The Sociology of Death.* Oxford: Blackwell.

Clarke, Adele E (1990), 'A social worlds research adventure: the case of reproductive science', in Cozzens, SE and TF Gieryn (eds.), *Theories of Science in Society.* Bloomington and Indianapolis: Indiana University Press.

Clifford, James (1990), 'Notes on (field)notes,' pp. 47-70 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Clifford, James and George E Marcus (1986) (eds.), *Writing Culture: The Poetics and Politics of Ethnography.* Berkeley: University of California Press.

Cline, Sally (1995), *Lifting the Taboo: Women, Death and Dying*. London: Little, Brown.

Cobb, Mark and Robshaw, Vanessa (1998) (eds.), *The Spiritual Challenge of Health Care*. Edinburgh and London: Churchill Livingstone.

Cockburn, Cynthia (1985), *Machinery of Dominance: Women, Men and Technical Know-How*. London: Pluto.

Cockburn, Cynthia (1983), *Brothers: Male Dominance and Technological Change*. London: Pluto.

Code, Lorraine (1995), *Rhetorical Spaces: Essays on Gendered Locations*. New York and London: Routledge.

Code, Lorraine (1991), *What Can She Know? Feminist Theory and the Constitution of Knowledge*. Ithaca: New York: Cornell University Press.

Code, Lorraine (1988), 'Experience, knowledge and responsibility,' pp. 187-204 in Griffiths, M and M Whitford (eds.), *Feminist Perspectives in Philosophy*. Bloomington, IN: Indiana University Press.

Code, Lorraine (1987/92), 'Persons and others,' pp. 89-107 in Shogan, D (ed.), *A Reader in Feminist Ethics*. Toronto: Canadian Scholars' Press.

Coles, Robert (1989), *The Call of Stories*. Boston, MA: Houghton Mifflin.

Collins, Harry (1991), 'Captives and victims: response to Scott, Richards and Martin', *Science, Technology and Human Values*, 16 (2): 249-51.

Collins, Harry and Steven Yearley (1992a), 'Epistemological chicken,' pp. 301-26 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Collins, Harry and Steven Yearley (1992b), 'Journey into space,' pp. 369-89 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Collins, Patricia Hill (1991), *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. New York and London: Routledge.

Collins, Patricia Hill (1989/1996), 'The social construction of Black feminist thought,' pp 222-48 in Garry, A and M Pearsall (eds.), *Women, Knowledge and Reality: Explorations in Feminist Philosophy*. New York and London: Routledge.

Connolly, Paul (1996), 'Doing what comes naturally? Standpoint epistemology, critical social research and the politics of identity,' in Lyon, ES and Busfield, J (eds.), *Methodological Imaginations.* London and Basingstoke: Macmillan.

Corner, Jessica (2003), 'The multi-disciplinary team – fact or fiction?' *European Journal of Palliative Care*, 10 (2): 10-12.

Corner, Jessica (1996), 'Is there a research paradigm for palliative care?' *Palliative Medicine*, 10: 201-8.

Corr, Charles A and Corr, Donna M (1983), *Hospice Care: Principles and Practice.* London: Faber and Faber.

Coupland, Justine, Coupland, Nikolas and Jeffrey D Robinson (1992), '"How are you?": negotiating phatic communion,' *Language in Society*, 21: 207-30.

Coyner, Sandra (1983), 'Women's studies as an academic discipline: why and how to do it,' pp. 46-71 in Bowles, G and Klein, RD (eds.), *Theories of Women's Studies.* London: Routledge and Kegan Paul.

Cozzens, Susan E and Gieryn, Thomas F (1990) (eds.), *Theories of Science in Society.* Bloomington and Indianapolis: Indiana University Press.

Creath, Richard (1996), 'The unity of science: Carnap, Neurah and beyond,' pp. 158-69 in Galison, P and Stump DJ (eds.), *The Disunity of Science: Boundaries, Contexts and Power.* Stanford, CA: Stanford University Press.

Csordas, Thomas J (1994) (ed.), *Embodiment and Experience: The Existential Ground of Culture and Self.* Cambridge: Cambridge University Press.

Csordas, Thomas J (1989), 'Embodiment as a paradigm for anthropology', *Ethos*, 18 (1): 5-47.

Csordas, Thomas J and Arthur Kleinman (1996), 'The therapeutic process,' pp. 3-20 in Sargent, CF and TM Johnson (eds.), *Medical Anthropology: Contemporary Theory and Method*, revised edition. Westport, CN and London: Praeger.

Curtis, Liz (1984), *Nothing But the Same Old Story: The Roots of Anti-Irish Racism.* London: Information on Ireland.

Curzer, H (1993a), 'Fry's concept of care in nursing ethics,' *Hypatia*, 8: 174-83.

D

Daly, Mary (1978), *Gyn/Ecology: The Metaethics of Radical Feminism.* Boston: Beacon Press.

Damasio, Antonio R (1995), *Descartes' Error: Emotion, Reason and the Human Brain.* London: Picador.

Davies, Celia (1995), *Gender and the Professional Predicament in Nursing.* Buckingham and Bristol, PA: Open University Press.

Davies, Christie (2002), 'Modernity and the "demoralised" afterlife,' paper presented at 6th International Conference on Death, Dying and Disposal, York, Sept 2002.

Davies, Karen (1990), *Women, Time and the Weaving of the Strands of Everyday Life.* Aldershot: Avebury.

Davion, Victoria (1991), 'Integrity and radical change,' pp. 180-92 in Card, C (ed.), *Feminist Ethics.* Kansas: University Press of Kansas.

de Groot, Joanna (1997), 'After the ivory tower: gender, commodification and the 'academic',' *Feminist Review*, 55: 130-42.

de Hennezel, Marie (1995; translated by Janeway, Carol Brown, 1998), *Intimate Death.* London: Little, Brown.

Dehli, Kari (1991), 'Leaving the comfort of home: working through feminisms,' in Bannerji H, Carty L, Dehli K, Heald S and K McKenna, *Unsettling Relations: The University as a Site of Feminist Struggles.* Toronto: Women's Press.

Deleuze, Gilles and Guattari, Félix (1988), *A Thousand Plateaus: Capitalism and Schizophrenia.* London: Athlone Press.

Denzin, Norman K and Yvonne S Lincoln (eds.) (1994), *Handbook of Qualitative Research.* Sage, London

Deutscher, Irwin (1976), 'Words versus deeds: words and deeds: social science and social policy,' pp. 25-49 in Sanders, WB (ed.), *The Sociologist as Detective: An Introduction to Research Methods.* New York: Praeger.

Deutscher, Irwin (1973), *What We Say/What We Do: Sentiments and Acts.* Glenview, IL: Scott Foresman.

Devault, Marjorie L (1990), 'Talking and listening from women's standpoint: feminist strategies for interviewing and analysis,' *Social Problems,* 37 (1): 96-116.

di Leonardo, Micaela (1998), *Exotics at Home: Anthropologies, Others, American Modernity.* Chicago and London: University of Chicago Press.

di Leonardo, Micaela (1991) (ed.), *Gender at the Crossroads of Knowledge: Feminist Anthropology in the Postmodern Era.* Berkeley, LA, Oxford: University of California Press.

Dingwall, Robert and Murray, Topsy (1983), 'Categorization in accident departments: 'good' patients, 'bad' patients and 'children,' *Sociology of Health and Illness*, 5 (2): 127-48.

Dom, Henry T (1999), 'Vaisnava Hindu and Ayurvedic approaches to caring for the dying,' *Innovations in End-of-Life Care*, 1(6), www.edc.org/lastacts/archives/archivesNov99/intlpersp.asp

Doyal, Lesley (1985), 'Women and the crisis in the National Health service,' pp. 154-60 in Ungerson, C (ed.), *Women And Social Policy: A Reader.* London: Macmillan.

du Bois, Barbara (1983), 'Passionate scholarship: notes on values, knowing and method in feminist social science,' pp. 105-16 in Bowles, G and Klein, RD (eds.), *Theories of Women's Studies.* London: Routledge and Kegan Paul.

du Boulay, Shirley (1984), *Cicely Saunders: The Founder of the Modern Hospice Movement.* London: Hodder & Stoughton.

Duhem, Pierre (1906/54), *The Aim and Structure of Physical Theory.* Princeton: Princeton University Press.

Dyck, Noel (2000), 'Home field advantage? Exploring the social construction of children's sports,' pp. 32-53 in Amit, V (ed.) *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

E

Edwards, Derek (1997), *Discourse and Cognition.* London, Thousand Oaks, New Delhi: Sage.

Edwards, Jeanette and Franklin, Sarah (1999, 2nd edition), *Technologies of Procreation: Kinship in the Age of Assisted Conception.* London: Routledge.

Ehrlich, Carol (1977), *Socialism, Anarchism and Feminism.* London: Dark Star.

Eire, Carlos MN (1990), 'Major problems in the definition of spirituality as an academic discipline,' pp. 53-61 in Hanson, BC (ed.), *Modern Christian Spirituality: Methodological and Historical Essays.* Atlanta, GA: Scholars Press.

Eliade, Mircea (1981, trans Mac L Ricketts), *Autobiography, Volume 1: 1907-1937 Journey East, Journey West.* San Francisco: Harper and Row.

Ellis, Carolyn and Flaherty, Michael (eds.) (1992), *Investigating Subjectivity: Research on Lived Experience*. London, Newbury Park, New Delhi: Sage.

Elshtain, Jean Bethke (1992), 'The power and powerlessness of women,' in Bock, G and James, S (eds.), *Beyond Equality and Difference: Citizenship, Feminist Politics and Female Subjectivity*. London and New York: Routledge.

Englehardt, H Tristram (1986; 1996 2nd edition), *Foundations of Bioethics*. Oxford and New York: Oxford University Press.

Evans-Pritchard, E E (1956), 'Fieldwork and the empirical tradition,' in *Social Anthropology and Other Essays*. New York: Free Press.

F

Farmer, Elizabeth (ed.) (1996), *Exploring the Spiritual Dimension of Care/in Caring*. Salisbury: Quay Books.

Faulkner, William (1935/96), *As I Lay Dying*. London: Random House.

Field, David (2000), 'What do we mean by 'psychosocial'? A discussion paper on use of the concept within palliative care,' National Council for Hospice and Specialist Palliative Care Services. London: National Council for Hospice and Specialist Palliative Care Services.

Field, David (1994), 'Palliative medicine and the medicalization of death,' *European Journal of Cancer Care*, 3: 58-62.

Field, David (1989), *Nursing the Dying*. London: Tavistock/Routledge.

Field, David, Hockey, Jenny and Neil Small (eds.) (1997), *Death, Gender and Ethnicity*. London and New York: Routledge.

Finch, Janet and Groves, Dulcie (1985), 'Community care and the family: a case for equal opportunities?' pp. 218-42 in Ungerson, C (ed.), *Women And Social Policy: A Reader*. London: Macmillan.

Finch, Janet and Groves, Dulcie (eds.) (1983), *A Labour of Love: Women, Work and Caring*. London: Routledge and Kegan Paul.

Fine, Arthur (1996), 'Science made up: constructivist sociology of scientific knowledge,' pp. 231-54 in Galison, P and Stump DJ (eds.), *The Disunity of Science: Boundaries, Contexts and Power*. Stanford, CA: Stanford University Press.

Fine, Michelle (1994), 'Working the hyphens: reinventing self and other in qualitative research,' pp. 70-82 in Denzin, NK and Lincoln YS (eds.), *Handbook of Qualitative Research*. London: Sage.

Flaherty, Michael (1992), 'Erotics and hermeneutics of temporality,' pp. 141-55 in Ellis, C and Flaherty, M (eds.), *Investigating Subjectivity: Research on Lived Experience*. London, Newbury Park, New Delhi: Sage.

Flanagan, Owen and Jackson, Kathryn (1987/93), 'Justice, care, and gender: the Kohlberg-Gilligan debate revisited,' pp. 69-84 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives*. New York and London: Routledge.

Flax, Jane (1992), 'Beyond equality: gender, justice and difference,' in Bock, G and James, S (eds.), *Beyond Equality and Difference: Citizenship, Feminist Politics and Female Subjectivity*. London and New York: Routledge.

Flax, Jane (1990), *Thinking Fragments: Psychoanalysis, Feminism and Postmodernism in the Contemporary West*. Berkeley: University of California Press.

Flax, Jane (1987), 'Postmodernism and gender relations in feminist theory,' *Signs: A Journal of Women in Culture and Society*, 12(4): 633-57.

Fleck, Ludwik (1935/79; edited by Trenn, TJ and RK Merton; translated by Bradley, F and TJ Trenn), *Genesis and Development of a Scientific Fact*. Chicago and London: University of Chicago Press.

Fleischman, Suzanne (1998), 'Gender, the personal and the voice of scholarship: a viewpoint,' *Signs*, 23 (4): 975-1016.

Foucault, Michel (edited by Colin Gordon, 1980), *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977*. Hemel Hempstead: Harvester Wheatsheaf.

Foucault, Michel (1979; translated by Robert Hurley), *History of Sexuality, Volume I: An Introduction*. Harmondsworth: Penguin.

Foucault, Michel (1979; translated by Alan Sheridan), *Discipline and Punish: The Birth of the Prison*. Harmondsworth: Penguin.

Fox, Richard G (ed.), *Recapturing Anthropology: Working in the Present*. Santa Fe: School of American Research Press.

Frankenburg, Ronald (ed.) (1992), *Time, Health and Medicine*. London: Sage.

Frankl, Viktor E (1946; revised edition 1964), *Man's Search for Meaning*. London: Hodder and Stoughton.

Fraser, Nancy (1989), *Unruly Practices: Power, Discourse and Gender in Contemporary Social Theory*. Minneapolis: University of Minnesota Press.

Freire, Paulo (1970) (trans: Myra Bergman Ramos), *Pedagogy of the Oppressed*. New York: Seabury Press.

Friedman, Marilyn (1987/93), 'Beyond caring: the de-moralization of gender,' pp. 258-73 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives*. New York and London: Routledge.

Froggatt, Katherine (1998), 'The place of metaphor and language in exploring nurses' emotional work,' *Journal of Advanced Nursing*, 28 (2): 332-8.

Frye, Marilyn (1983), *The Politics of Reality: Essays in Feminist Theory*. Trumansburg, NY: Crossing Press.

Frye, Marilyn (1991), 'A response to *Lesbian Ethics*: Why *Ethics*?' pp. 52-9 in Card, C (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Fujimura, Joan (1992), 'Crafting science: standardized packages, boundary objects, and "translation",' pp. 168-211 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Fulford, KWM, Ersser, Steven and Tony Hope (eds.) (1996), *Essential Practice in Patient-Centred Care*. Oxford: Blackwell.

G

Gabe, Jonathan, Kelleher, David and Gareth Williams (eds.) (1994), *Challenging Medicine*. London: Routledge.

Gablik, Suzi (1984), *Has Modernism Failed?* London: Thames and Hudson.

Galison, Peter (1996a), 'Introduction: the context of disunity,' pp. 1-33 in Galison, P and Stump DJ (eds.), *The Disunity of Science: Boundaries, Contexts and Power*. Stanford, CA: Stanford University Press.

Galison, Peter (1996b), 'Computer simulations and the trading zone,' pp. 118-57 in Galison, P and Stump DJ (eds.) , *The Disunity of Science: Boundaries, Contexts and Power*. Stanford, CA: Stanford University Press.

Galison, Peter (1987), *How Experiments End*. Chicago and London: University of Chicago Press.

Galison, Peter and Stump, David J (1996) (eds.), *The Disunity of Science: Boundaries, Contexts and Power.* Stanford, CA: Stanford University Press.

Garfinkel, Harold (1967), *Studies in Ethnomethodology.* Englewood Cliffs, NJ: Prentice-Hall.

Garry, Ann and Marilyn Pearsall (eds.) (1996; 2nd edition), *Women, Knowledge and Reality: Explorations in Feminist Philosophy.* New York and London: Routledge.

Geertz, Clifford (1973), *The Interpretation of Cultures.* New York: Basic Books.

George, Susan (1988), *A Fate Worse Than Debt.* Harmondsworth: Penguin.

Gilligan, Carol (1992/98), 'Getting civilized,' pp. 13-28 in Oakley, A and Mitchell, J (eds.), *Who's Afraid of Feminism: Seeing Through the Backlash.* Harmondsworth: Penguin.

Gilligan, Carol (1987/88), 'Prologue: adolescent development reconsidered,' in Gilligan, C, et al. (eds.), *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education.* Cambridge, MA and London: Harvard University Press.

Gilligan, Carol (1986/88), 'Remapping the moral domain: new images of self in relationship,' in Gilligan, C, et al. (eds.), *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education.* Cambridge, MA and London: Harvard University Press.

Gilligan, Carol (1986/93), 'Reply to critics,' pp. 207-14 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Gilligan, Carol (1982/93), *In a Different Voice: Psychological Theory and Women's Development.* Cambridge, MA and London: Harvard University Press.

Gilligan, Carol and Attanucci, Jane (1988), 'Two moral orientations,' in Gilligan, C, Ward, JV, Taylor, JMcL with B Bardige (eds.), *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education.* Cambridge, MA and London: Harvard University Press.

Gilligan, Carol, Janie Victoria Ward, Jill McLean Taylor with Betty Bardige (eds.) (1988), *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education.* Cambridge, MA and London: Harvard University Press.

Glaser, Barney G (1992), *Emergence vs Forcing: Basics of Grounded Theory Analysis.* Mill Valley, CA: Sociology Press.

Glaser, Barney G and Strauss, Anselm L (1967), *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago, IL and New York: Aldine.

Glaser, Barney G and Strauss, Anselm L (1966), *Awareness of Dying.* London: Weidenfeld.

Goffman, Erving (1971), *The Presentation of Self in Everyday Life.* Harmondsworth: Penguin.

Goffman, Erving (1967), *Interaction Ritual: Essays on Face-to-face Behaviour.* New York: Doubleday.

Goldberger, Nancy R, Tarule, Jill, Clinchy, Blythe and Mary Belenky (1996), *Knowledge, Difference and Power.* New York: Basic Books.

Goleman, Daniel (1997), *Emotional Intelligence.* London: Bloomsbury.

Good, Byron J (1994), *Medicine, Rationality and Experience: An Anthropological Perspective.* Cambridge: Cambridge University Press.

Good, Byron J and Good, Mary-Jo DelVecchio (1993), '"Learning medicine": the constructing of medical knowledge at Harvard Medical School,' pp. 81-107 in Lindenbaum, S and Lock, M (eds.), *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life.* Berkeley, Los Angeles, London: University of California Press.

Good, Mary-Jo Delvecchio, Brodwin, Paul E, Good, Byron J and Arthur Kleinman (1992) (eds.), *Pain as Human Experience: An Anthropological Perspective.* Berkeley: University of California Press.

Gordon, Deborah (1995), 'Conclusion,' pp. 429-41 in Behar, R and D Gordon (eds.), *Women Writing Culture.* Berkeley, Los Angeles, London: University of California Press.

Gordon, Deborah (1988), 'Tenacious assumptions in western medicine,' pp. 19-56 in Lock, M and D Gordon (eds.), *Biomedicine Examined.* Dordrecht, Boston and London: Kluwer.

Griffin, Susan (1978), *Woman and Nature: The Roaring Inside Her.* New York: Harper and Row.

Griffiths, Morwenna and Margaret Whitford (1988) (eds.), *Feminist Perspectives in Philosophy.* Bloomington, IN: Indiana University Press.

Gross, Paul R, Levitt, Norman and Martin W Lewis (1996) (eds.), *The Flight from Science and Reason.* New York: New York Academy of Sciences.

Grossman, Ashley (1988), 'Opioid peptides and pain,' in Mann, RD (ed.), *History of the Management of Pain*. Carnforth, Lancs: Parthenon

Gupta, Akhil and Ferguson, James (1997), 'Introduction,' pp. 1-26 in Gupta, A and J Ferguson (eds.), *Anthropological Locations: Boundaries and Grounds of a Field Science*. Berkeley: University of California Press.

Gupta, Akhil and Ferguson, James (eds.) (1997), *Anthropological Locations: Boundaries and Grounds of a Field Science*. Berkeley: University of California Press.

H

Hacker, Sally (1990) (edited by Smith, Dorothy E and Turner, Susan M), *"Doing It The Hard Way": Investigations of Gender and Technology*. Boston and London: Unwin Hyman.

Hacker, Sally (1989), *Pleasure, Power and Technology: Some Tales of Gender, Engineering and the Cooperative Workplace*. Boston: Unwin Hyman.

Hacking, Ian (1992), 'The self-vindication of the laboratory sciences,' pp. 29-64 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Hacking, Ian (1983), *Representing and Intervening: Introductory Topics in the Philosophy of Natural Science*. Cambridge: Cambridge University Press.

Hammersley, Martyn (1989), *The Dilemma of Qualitative Method: Herbert Blumer and the Chicago Tradition.* London and New York: Routledge.

Hammersley, Martyn and Atkinson, Paul (1983), *Ethnography: Principles in Practice*. London: Tavistock.

Hampson, Daphne (1996), *After Christianity.* London: SCM Press.

Hanen, Marsha and Nielsen, Kai (eds.) (1987), *Science, Morality and Feminist Theory*. Calgary, Alberta, Canada: University of Calgary Press.

Haney, Eleanor (1980), 'What is feminist ethics? A proposal for continuing discussion,' *Journal of Religious Ethics*, 8: 115-24.

Hanson, Bradley C (ed.) (1990), *Modern Christian Spirituality: Methodological and Historical Essays*. Atlanta, GA: Scholars Press.

Haraway, Donna J (1997), *Modest_Witness@Second_Millenium.FemaleMan©_ Meets_ OncoMouse™: Feminism and Technoscience*. New York and London: Routledge.

Haraway, Donna J (1996), 'Modest witness: feminist diffractions in science studies,' pp. 428-41 in Galison, P and Stump DJ (eds.) , *The Disunity of Science: Boundaries, Contexts and Power*. Stanford, CA: Stanford University Press.

Haraway, Donna J (1991), *Simians, Cyborgs and Women: The Reinvention of Nature*. London: Free Association Books.

Haraway, Donna J (1989), *Primate Visions: Gender, Race and Nature in the World of Modern Science*. London: Routledge, Chapman and Hall.

Haraway, Donna (1988), 'Situated knowledges: the science question in feminism and the privilege of partial perspective,' *Feminist Studies*, 14 (3): 575-99.

Harding, Sandra (1998), *Is Science Multicultural?: Postcolonialisms, Feminisms, and Epistemologies*. Bloomington, Ind: Indiana University Press.

Harding, Sandra (1994), 'Is science multicultural? Challenges, resources, opportunities, uncertainties,' *Configurations*: 301-30.

Harding, Sandra (ed.) (1993), *The "Racial" Economy of Science: Toward a Democratic Future*. Bloomington & Indianapolis, Ind: Indiana University Press.

Harding, Sandra (1991), *Whose Science? Whose Knowledge? Thinking from Women's Lives*. Milton Keynes: Open University Press.

Harding, Sandra (1987a), 'Conclusion: epistemological questions,' pp. 181-90 in Harding, S (ed.), *Feminism and Methodology: Social Science Issues*. Bloomington and Indianapolis: Indiana University Press; Milton Keynes: Open University Press.

Harding, Sandra (1987b), 'Introduction: is there a feminist method?' pp. 1-14 in Harding, S (ed.), *Feminism and Methodology: Social Science Issues*. Bloomington and Indianapolis: Indiana University Press; Milton Keynes: Open University Press.

Harding, Sandra (1986), *The Science Question in Feminism*. Milton Keynes: Open University Press.

Harré, Rom (1986), 'An outline of the social constructionist viewpoint,' in Harré, R (ed.), *Social Construction of Emotions*. New York and Oxford: Blackwell.

Harrison, Judy, Maguire, Peter and Carolyn Pitceathly (1995), 'Confiding in crisis: gender differences in patterns of confiding among cancer patients,' *Social Science and Medicine*, 41 (9): 1255-60.

Hastrup, Kirsten (1987), 'Fieldwork among friends: ethnographic exchange within the Northern civilization,' pp 94-108 in Jackson, A (ed.), *Anthropology at Home.* Association of Anthropologists, London and New York: Tavistock.

Hastrup, Kirsten and Peter Hervik (eds.) (1994), *Social Experience and Anthropological Knowledge.* European Association of Social Anthropologists, London: Routledge.

Hearn, Jeff (1985), 'Patriarchy, professionalisation and the semi-professions,' pp. 190-206 in Ungerson, Clare (ed), *Women And Social Policy: A Reader.* London: Macmillan.

Hekman, Susan J (1995), *Moral Voices, Moral Selves: Carol Gilligan and Feminist Moral Theory.* Cambridge and Oxford: Polity Press.

Hekman, Susan J (1990), *Gender and Knowledge: Elements of a Postmodern Feminism.* Cambridge: Polity Press.

Held, Virginia (1987), 'Non-contractual society,' pp. 111-37 in Hanen, M and Nielsen, K (eds.), *Science, Morality and Feminist Theory.* Calgary, Alberta, Canada: University of Calgary Press.

Highfield, Martha and C Cason (1983), 'Spiritual needs of patients: are they recognized?' *Cancer Nursing*, 6 (3): 187-92.

Hillier, E Richard (1983), 'Terminal care in the United Kingdom', pp. 319-34 in Corr, CA and Corr, DM (eds.), *Hospice Care: Principles and Practice.* London: Faber and Faber.

Hirsch, Marianne and Keller, Evelyn Fox (eds.) (1990), *Conflicts in Feminism.* London: Routledge.

Hoagland, Sarah L (1991), 'Some thoughts about "caring",' pp. 246-63 in Card, C (ed.), *Feminist Ethics.* Kansas: University Press of Kansas.

Hoagland, Sarah L (1988), *Lesbian Ethics.* Palo Alto, CA: Institute of Lesbian Studies.

Hochschild, Arlie Russell (1983), *The Managed Heart: Commercialization of Human Feeling.* Berkeley, Los Angeles, London: University of California Press.

Hockey, Jenny (2002), 'Dying the way we live,' pp. 51-63 in Rumbold, B (ed.) *Spirituality and Palliative Care: Social and Pastoral Perspectives.* Melbourne, Oxford and New York: Oxford University Press.

Hockey, Jennifer L (1990), *Experiences of Death: An Anthropological Account*. Edinburgh: Edinburgh University Press.

Hockey, Jenny and James, Allison (1993), *Growing Up and Getting Old: Ageing and Dependency in the Life Course*. London and Newbury Park, CA: Sage

Hockey, Jenny, Katz, Jeanne and Neil Small (eds.) (2001), *Grief, Mourning and Death Ritual*. Buckingham: Open University Press.

Hockley, JM (1992), 'Protracted dying and the grieving process', unpublished MSc dissertation, University of Edinburgh.

Hollis, Martin and Lukes, Steven (eds.) (1982), *Rationality and Relativism.* Cambridge, MA: MIT Press.

Horton, Robin (1967a), 'African traditional thought and western science: part 1,' *Africa*, 37: 50-71.

Horton, Robin (1967b), 'African traditional thought and western science: part 2,' *Africa*, 37: 155-87.

Houston, Barbara (1990/1992), 'Prolegomena to future caring,' pp. 109-28 in Shogan, D (ed.), *A Reader in Feminist Ethics*. Toronto: Canadian Scholars' Press.

Houston, Barbara and Diller, Ann (1992), 'Trusting ourselves to care,' pp. 373-82 in Shogan, D (ed.), *A Reader in Feminist Ethics*. Toronto: Canadian Scholars' Press.

Howell, Nancy (1990), *Surviving Fieldwork: A Report of the Advisory Panel on Health and Safety in Fieldwork, American Anthropological Association.* Washington, DC: American Anthropological Association.

Huizer, Gerrit (1991), 'Participatory research and healing witchcraft: an essay in the anthropology of crisis,' pp. 40-58 in Nencel, Lorraine and Pels, Peter (eds.), *Constructing Knowledge: Authority and Critique in Social Science*. London, Newbury Park, New Delhi: Sage.

Hunt, AH (1993), 'Humour as a nursing intervention,' *Cancer Nursing*, 16 (1): 34-9.

Hymes, Dell (1977), *Foundations in Sociolinguistics: An Ethnographic Approach.* Philadelphia: University of Pennsylvania Press.

I

Ignatieff, Michael (1984/1994), *The Needs of Strangers*. London: Random House.

Illich, Ivan (1995), *The Limits to Medicine: Medical Nemesis: The Expropriation of Health*. London: Boyars.

Institute of Nursing, University of Leeds, National Health Service Executive, Northern Yorkshire (1995), *A Framework for Spiritual Faith and Related Pastoral Care*. Manchester: Barkers.

Isaksen, Astrid S and Eva Gjengedal (2000), 'The significance of fellow patients for the patient with cancer: what can nurses do?' *Cancer Nursing*, 23 (5): 382-91.

J

Jackson, Anthony (1987), 'Reflections on ethnography at home and the ASA,' pp. 1-15 in Jackson, A (ed.), *Anthropology at Home.* Association of Anthropologists, London and New York: Tavistock.

Jackson, Jean (1994), 'Chronic pain and the tension between the body as subject and object,' pp. 201-28 in Csordas, TJ (ed.), *Embodiment and Experience: The Existential Ground of Culture and Self.* Cambridge: Cambridge University Press.

Jackson, Jean (1990), '"I am a fieldnote": fieldnotes as a symbol of professional identity,' pp. 3-34 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Jackson, Michael (ed.) (1989), *Paths Toward a Clearing: Radical Empiricism and Ethnographic Inquiry* Bloomington: Indiana University Press.

Jaggar, Alison M (1991), 'Feminist ethics: projects, problems, prospects,' pp. 78-104 in Card, C (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Jaggar, Alison (1989), 'Love and knowledge: emotion in feminist epistemology,' in Jaggar, A and Bordo, S (eds.), *Gender/Body/Knowledge*. New Brunswick, NJ: Rutgers University Press.

Jaggar, Alison M (1983), *Feminist Politics and Human Nature.* Brighton: Harvester Press.

Jaggar, Alison and Bordo, Susan (eds.) (1989), *Gender/Body/Knowledge*. New Brunswick, NJ: Rutgers University Press.

Jaggar, Alison M and Struhl, Paula R (1978) (eds.), *Feminist Frameworks: Alternative Theoretical Accounts of the Relations between Women and Men.* New York: McGraw-Hill.

James, Allison, Hockey, Jenny and Andrew Dawson (1997), 'Introduction: the road from Santa Fe,' pp. 1-28 in James, A, Hockey, J and A Dawson (eds.), *After Writing*

Culture: Epistemology and Praxis in Contemporary Anthropology. London and New York: Routledge.

James, Allison, Hockey, Jenny and Andrew Dawson (eds.) (1997), *After Writing Culture: Epistemology and Praxis in Contemporary Anthropology.* London and New York: Routledge.

James, Nicky (1992), 'Care = organisation + physical labour + emotional labour,' *Sociology of Health and Illness*, 14 (4): 488-509.

James, Nicky (1986), 'Care and work in nursing the dying,' unpublished PhD thesis, University of Aberdeen.

James, Nicky and Field, David (1992), 'The routinization of hospice: charisma and bureaucratization', *Social Science and Medicine*, 34 (12): 1363-75.

James, Veronica and Gabe, Jonathan (eds.) (1996), *Health and the Sociology of Emotions.* Oxford and Cambridge, MA: Blackwell.

James, Veronica and Gabe, Jonathan (1996), 'Connecting emotions and health,' pp. 1-23 in James, V and Gabe, J (eds.), *Health and the Sociology of Emotions.* Oxford and Cambridge, MA: Blackwell.

Jayaratne, Toby E (1983), 'The value of quantitative methodology for feminist research,' pp. 140-61 in Bowles, G and Klein, RD (eds.), *Theories of Women's Studies*. London: Routledge and Kegan Paul.

Jefferson, Gail (1984), 'On the organization of laughter in talk about troubles,' pp. 346-69 in Atkinson, JM and Heritage, J (eds.), *Structures of Social Action: Studies in Conversation Analysis*. Cambridge: Cambridge University Press.

Jeffrey, Roger (1979), 'Normal rubbish: deviant patients in casualty departments,' *Sociology of Health and Illness*, 1 (1): 90-108).

Johnson, Anne (1998), 'The notion of spiritual care in professional practice,' pp. 151-66 in Cobb, M and Robshaw, V (eds.), *The Spiritual Challenge of Health Care*. Edinburgh and London: Churchill Livingstone.

Johnson, Martin and Webb, Christine (1995), 'Rediscovering unpopular patients: the concept of social judgement,' *Journal of Advanced Nursing*, 21: 466-75,

K

Kaminer, Wendy (1984), *Women Volunteering*. Garden City, NY: Anchor.

Kearney, Michael (1992), 'Palliative medicine: just another specialty?', *Palliative Medicine*, 6: 39-46.

Kellehear, Allan (2000), 'Spirituality and palliative care: a model of needs,' *Palliative Medicine*, 14: 149-55.

Kellehear, Allan (1990), *Dying of Cancer: The Final Year of Life*. Chur: Harwood Academic Press.

Keller, Evelyn Fox (1996), 'The dilemma of scientific subjectivity in postvital culture,' pp. 417-27 in Galison, P and Stump DJ (eds.) , *The Disunity of Science: Boundaries, Contexts and Power*. Stanford, CA: Stanford University Press.

Keller, Evelyn Fox (1992), *Secrets of Life, Secrets of Death: Essays on Language, Gender and Science*. New York and London: Routledge.

Keller, Evelyn Fox (1985), *Reflections on Gender and Science*. New Haven, Conn: Yale University Press.

Kirmayer, Lawrence J (1988), 'Mind and body as metaphors: hidden values in biomedicine,' pp. 57-93 in Lock M and DR Gordon (eds.), *Biomedicine Examined*. Dordrecht, Boston and London: Kluwer.

Kitzinger, Celia and Alison Thomas (1995), 'Sexual harassment: a discursive approach,' pp. 32-48 in Wilkinson, S and C Kitzinger (eds.), *Feminism and Discourse: Psychological Perspectives*. London, Thousand Oaks, New Delhi: Sage

Klagsbrun, Samuel C (1981), 'Hospice - a developing role,' pp. 5-8 in Saunders, C, Summers, DH and N Teller (eds.), *Hospice: The Living Idea*. London: Edward Arnold.

Klein, Renate D (1983), 'How to do what we want to do: thoughts about feminist methodology,' pp. 88-104 in Bowles, G and RD Klein (eds.), *Theories of Women's Studies*. London: Routledge and Kegan Paul.

Kleinman, Arthur (1995), *Writing at the Margin: Discourse Between Anthropology and Medicine*. London and California: University of California Press.

Knorr-Cetina, Karin (1993), 'Strong constructivism - from a sociologist's point of view: a personal addendum to Sismondo's paper', *Social Studies of Science*, 23: 555-562.

Knorr Cetina, Karin (1992), 'The couch, the cathedral, and the laboratory: on the relationship between experiment and laboratory in science,' pp. 113-38 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Kohlberg, Lawrence (1981), 'Indoctrination versus relativity in moral education,' in *The Philosophy of Moral Development*, vol. 1. San Francisco: Harper and Row.

Kondo, Dorinne K (1990), *Crafting Selves: Power, Gender and Discourses of Identity in a Japanese Workplace.* Chicago and London: University of Chicago Press.

Kornegger, Peggy (1975), *Anarchism: The Feminist Connection.* London: Dark Star.

Kothari, Manu L and Lopa A Mehta (1988), 'Violence in modern medicine,' pp. 167-210 in Nandy, A (ed.), *Science, Hegemony and Violence: A Requiem for Modernity.* New Delhi and Oxford: Oxford University Press.

Kristeller, Jean L, Zumbrum, Collette S and Robert F Schilling (1999), ''I would if I could': how oncologists and oncology nurses address spiritual distress in cancer patients,' *Psycho-Oncology*, 8 (5): 451-8.

Kropotkin, Petr AK (1908/87), *Mutual Aid: A Factor of Evolution.* London: Freedom Press.

Kübler-Ross, Elisabeth (1995), *Death Is Of Vital Importance: On Life, Death, and Life After Death.* New York: Station Hill Press.

Kübler-Ross, Elisabeth (1974), *Questions and Answers on Death and Dying.* New York: Macmillan.

Kübler-Ross, Elisabeth (1970), *On Death and Dying.* London: Tavistock.

Kuhn, Thomas S (1962; 2nd edition 1969), *The Structure of Scientific Revolutions.* Chicago: University of Chicago Press.

L

Lad, Vasant (1985), *Ayurveda: The Science of Self-Healing.* Santa Fe: Lotus Press.

Lakoff, George (1993), 'The contemporary theory of metaphor,' pp. 202-51 in Ortony, A (ed.), *Metaphor and Thought.* Cambridge and New York: Cambridge University Press.

Lakoff, George and Mark Johnson (1980), *Metaphors We Live By.* Chicago and London: University of Chicago Press.

Lange, Lynda (1992), 'Women have to exist to resist: the moral worth of persons and the question of whether or not women are a group,' pp. 187-204 in Shogan, D (ed.), *A Reader in Feminist Ethics.* Toronto: Canadian Scholars' Press.

Langley-Evans, Alison and Sheila Payne (1997), 'Light-hearted death talk in a palliative day care unit,' *Journal of Advanced Nursing*, 26: 1091-7

Larrabee, Mary (ed.) (1993), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Latour, Bruno (1993; translated by Catherine Porter) *We Have Never Been Modern.* New York and London: Harvester Wheatsheaf.

Latour, Bruno (1988), 'The politics of explanation: an alternative,' pp. 155-76 in Woolgar, S (ed.), *Knowledge and Reflexivity: New Frontiers in the Sociology of Knowledge*. London, Newbury Park, Beverly Hills, New Delhi: Sage.

Latour, Bruno (1987), *Science in Action.* Cambridge: Harvard University Press.

Lau, DC (1963/85), *Lao Tzu: Tao Te Ching.* London: Penguin.

Lave, Jean and Etienne Wenger (1991), *Situated Learning: Legitimate Peripheral Participation.* Cambridge: Cambridge University Press.

Law, John (1991) (ed.), *Power, Technology and the Modern World.* Oxford: Blackwell

Lawton, Julia (2000), *The Dying Process: Patients' Experiences of Palliative Care.* London and New York: Routledge.

Lazreg, Marina (1994), 'Women's experience and feminist epistemology: a critical neo-rationalist approach,' pp. 45-62 in Lennon, K and Whitford, M (eds.), *Knowing the Difference: Feminist Perspectives in Epistemology.* London and New York: Routledge.

Lederman, Rena (1990), 'Pretexts for ethnography: on reading fieldnotes,' pp. 71-91 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Lee, Richard B (1984), *The Dobe !Kung.* New York: Holt, Rinehart and Winston.

Lennon, Kathleen and Margaret Whitford (eds.) (1994), *Knowing the Difference: Feminist Perspectives in Epistemology.* London and New York: Routledge.

Lewin, Ellen and Virginia Olesen (eds.) (1985), *Women, Health and Healing: Toward a New Perspective.* New York and London: Tavistock.

Liashenko, J and Davis, A (1991), 'Nurses and physicians on nutritional support: a comparison,' *Journal of Medicine and Philosophy*, 16: 259-83.

Liddle, A Mark (1996), 'Gender, power and epistemology: can men know feminist truths?' in Lyon, ES and Busfield, J (eds.), *Methodological Imaginations.* London and Basingstoke: Macmillan.

Lindenbaum, Shirley and Lock, Margaret (eds.) (1993), *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life.* Berkeley, Los Angeles, London: University of California Press.

Lock, Margaret and Gordon, Deborah R (eds.) (1988), *Biomedicine Examined.* Dordrecht, Boston and London: Kluwer.

Lock, Margaret and Scheper-Hughes, Nancy (1996), 'A critical-interpretive approach in medical anthropology: rituals and routines of discipline and dissent,' pp. 41-70 in Sargent, CF and TM Johnson (eds.), *Medical Anthropology: Contemporary Theory and Method*, revised edition. Westport, CN and London: Praeger.

Longaker, Christine (1997), *Facing Death and Finding Hope: A Guide to the Emotional and Spiritual Care of the Dying.* London: Random House.

Lorde, Audre (1984), *Sister Outsider: Essays and Speeches.* Trumansburg, NY: Crossing Press.

Lugones, María (1991), 'On the logic of pluralist feminism,' pp. 35-44 in Card, C (ed.), *Feminist Ethics.* Kansas: University Press of Kansas.

Lugones, María (1990), 'Hispaneando y lesbiando: On Sarah Hoagland's *Lesbian Ethics*,' *Hypatia*, 5(3): 138-46.

Lugones, María (1987), 'Playfulness, 'World'-traveling and loving perception,' *Hypatia*, 2 (2): 3-19.

Lunn, Len (1990), 'Having no answer,' in Saunders, C (ed.), *Hospice and Palliative Care.* London: Edward Arnold.

Lupton, Deborah (1998), *The Emotional Self.* London, Thousand Oaks, New Delhi: Sage.

Lupton, Deborah (1994), *Medicine as Culture: Illness, Disease and the Body in Western Societies.* London, Thousand Oaks, New Delhi: Sage.

Lutz, Catherine (1995), 'The gender of theory,' pp. 249-66 in Behar, R and D Gordon (eds.), *Women Writing Culture.* Berkeley, Los Angeles, London: University of California Press.

Lutz, Catherine A (1990), 'Engendered emotion: gender, power, and the rhetoric of emotional control in American discourse,' pp. 69-91 in Lutz, CA and Abu-Lughod, L

(eds.), *Language and the Politics of Emotion*. Cambridge: Cambridge University Press.

Lutz, Catherine A (1988), *Unnatural Emotions: Everyday Sentiments on a Micronesian Atoll and their Challenge to Western Theory*. Chicago, IL and London: University of Chicago Press.

Lykke, Nina and Braidotti, Rosi (1996), *Between Monsters, Goddesses and Cyborgs: Feminist Confrontations with Science, Medicine and Cyberspace*. London: Zed Books.

Lynch, Michael (1993), *Scientific Practice and Ordinary Action: Ethnomethodology and Social Studies of Science*. Cambridge: Cambridge University Press.

Lynch, Michael (1992a), 'Extending Wittgenstein: the pivotal move from epistemology to the sociology of science,' pp. 215-65 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Lynch, Michael (1992b), 'From the "will to theory" to the discursive collage: a reply to Bloor's "left and right Wittgensteinians",' pp. 283-300 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Lynd, Robert (1939), *Knowledge for What?* Princeton, NJ: Princeton University Press.

Lyon, E Stina and Busfield, Joan (eds) (1996), *Methodological Imaginations*. London and Basingstoke: Macmillan.

Lyons, Nona Plessner (1983/88), 'Two perspectives: on self, relationships, and morality,' in Gilligan, C, Ward, JV, Taylor, JMcL with B Bardige (eds.), *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education*. Cambridge, MA and London: Harvard University Press.

M

MacCormack, Carol P and Strathern, Marilyn (eds.) (1980), *Nature, Culture and Gender*. Cambridge: Cambridge University Press.

Macdonald, Sharon (1997), 'The museum as mirror: ethnographic reflections,' pp. 161-76, in James, A, Hockey, J and A Dawson (eds.), *After Writing Culture: Epistemology and Praxis in Contemporary Anthropology*. London and New York, Routledge.

MacIntyre, Alasdair (1985), *After Virtue: A Study in Moral Theory*. London: Duckworth

MacKenzie, Donald (1981), *Statistics in Britain, 1865-1930: The Social Construction of Scientific Knowledge*. Edinburgh: Edinburgh University Press.

MacLeod, Martha LP (1990), 'Experience in everyday nursing practice: a study of "experienced" surgical ward sisters,' unpublished PhD thesis, University of Edinburgh.

Mair, Miller (1989), *Between Psychology and Psychotherapy: A Poetics of Experience*. London and New York: Routledge.

Mannheim, Karl (1952), *Essays on the Sociology of Knowledge*. London: Routledge and Kegan Paul.

Marcus, George E (1994/98), 'On ideologies of reflexivity in contemporary efforts to remake the human sciences,' in Marcus, George E, *Ethnography Through Thick and Thin*. Princeton, NJ: Princeton University Press.

Marcus, George E and Michael MJ Fischer (1986), *Anthropology as Cultural Critique: An Experimental Moment in the Human Sciences*. Chicago: University of Chicago Press.

Marks, Isaac and Scott, Robert (eds.) (1990), *Mental Health Care Delivery: Innovations, Impediments and Implementation*. Cambridge: Cambridge University Press.

Marris, Peter (1974; revised edition 1986), *Loss and Change*. London: Routledge and Kegan Paul.

Martin, Brian (1996), 'Sticking a needle into science: the case of polio vaccines and the origins of AIDS,' *Social Studies of Science*, 26 (2): 245-66.

Marx, Leo (1994/95), 'The idea of 'technology' and postmodern pessimism,' in Ezrahi, Y, Mendelsohn, E and H Segal (eds), *Technology, Pessimism, and Postmodernism*. Amherst, MA: University of Massachusetts Press.

Maslow, Abraham H (1954), *Motivation and Personality*. New York: Harper.

Maxwell, Nicholas (1984), *From Knowledge to Wisdom*. Oxford: Basil Blackwell.

May, Tim (1993), *Social Research: Issues, Methods and Process*. Buckingham: Open University Press.

Maynard, Mary and June Purvis (eds.) (1994), *Researching Womens' Lives from a Feminist Perspective*. London: Taylor and Francis.

Mazer, Thérèse M (1994), 'Death and dying in a hospice: an ethnographic study,' unpublished PhD thesis, University of Edinburgh.

McFall, Lynne (1991), 'What's wrong with bitterness?' pp. 146-60 in Card, C (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

McGrath, Pam (2002), 'Creating a language for 'spiritual pain' through research: a beginning,' *Supportive Care in Cancer*, 10: 637-46.

McSherry, Wilfred and Ross, Linda (2002), 'Dilemmas of spiritual assessment: considerations for nursing practice,' *Journal of Advanced Nursing*, 38(5): 479-88.

Mearns, David and Thorne, Brian (1999, 2nd edition), *Person-Centred Counselling in Action*. London, California and New Delhi: Sage.

Melia, Kath (1987), *Learning and Working: The Occupational Socialisation of Nurses*. London: Tavistock.

Mellor, Philip A (1993), 'Death in high modernity: the contemporary presence and absence of death,' pp. 11-30 in Clark, D (ed.), *The Sociology of Death*. Oxford: Blackwell.

Melzack, Ronald and Wall, Patrick D (1982, revised edition), *The Challenge of Pain*. Harmondsworth: Penguin.

Merton, Robert (1938/1970), *Science, Technology and Society in Seventeenth-Century England*. New York and London: Harper and Row.

Midgley, Mary (1996), *Utopias, Dolphins and Computers: Problems of Philosophical Plumbing*. London and New York: Routledge.

Midgley, Mary (1992), *Science as Salvation: A Modern Myth and its Meaning*. London: Routledge.

Midgley, Mary (1989/1995), *Wisdom, Information and Wonder: What is Knowledge For?* London: Routledge.

Mies, Maria (1983), 'Towards a methodology for feminist research,' pp. 117-39 in Bowles, G and RD Klein (eds.), *Theories of Women's Studies*. London: Routledge and Kegan Paul (later republished pp. 64-82 in Hammersley, M (ed.) (1993), *Social Research: Philosophy, Politics and Practice*. London, Newbury Park: Sage).

Milard, Regina (2002), 'Facing the situation,' pp. 97-115 in Rumbold, B (ed.), *Spirituality and Pastoral Care: Social and Pastoral Perspectives*. Melbourne, Oxford and New York: Oxford University Press.

Miles, Agnes (1991), *Women, Health and Medicine.* Buckingham and Bristol, PA: Open University Press.

Mishler, Elliot G (1981), *Social Contexts of Health, Illness, and Patient Care.* Cambridge: Cambridge University Press.

Moerman, Michael (1988), *Talking Culture: Ethnography and Conversation Analysis.* Philadelphia: University of Pennsylvania Press.

Moody-Adams, Michele M (1991), 'Gender and the complexity of moral voices,' pp. 195-212 in Card, C (ed.), *Feminist Ethics.* Kansas: University Press of Kansas.

Moore, Henrietta (1996), *The Future of Anthropological Knowledge.* London: Routledge.

Morgan, Elaine (1997), *The Aquatic Ape Hypothesis.* London: Souvenir Press.

Morgan, Elaine (1985; revised edition), *The Descent of Woman.* London: Souvenir Press.

Morgan, Jerry L (1993), 'Observations on the pragmatics of metaphor,' pp. 124-34 in Ortony, A (ed.), *Metaphor and Thought.* Cambridge and New York: Cambridge University Press.

Morsy, Soheir A (1996), 'Political economy in medical anthropology,' pp. 21-40 in Sargent, CF and TM Johnson (eds.), *Medical Anthropology: Contemporary Theory and Method*, revised edition. Westport, CN and London: Praeger.

Mulkay, Michael (1993), 'Social death in Britain,' pp. 31-49 in Clark, D (ed.), *The Sociology of Death.* Oxford: Blackwell.

Mulkay, Michael (1985), *The Word and the World: Explorations in the Form of Sociological Analysis.* London: Allen and Unwin.

Mullett, Sheila Mason (1987/92), 'Inclusive philosophy: feminist strategies for the recovery of persons,' pp. 69-88 in Shogan, D (ed.), *A Reader in Feminist Ethics.* Toronto: Canadian Scholars' Press.

Mullett, Sheila Mason (1992), 'Moral talk,' pp. 29-38 in Shogan, D (ed.), *A Reader in Feminist Ethics.* Toronto: Canadian Scholars' Press.

Murdoch, Iris (1970), *The Sovereignty of Good.* London: Routledge and Kegan Paul.

N

Nagel, Thomas (1986), *The View From Nowhere.* New York: Oxford University Press.

Nandy, Ashis (1988), 'Introduction: science as a reason of state,' pp. 1-23 in Nandy, A (ed.), *Science, Hegemony and Violence: A Requiem for Modernity.* New Delhi and Oxford: Oxford University Press.

Nandy, Ashis (ed.) (1988), *Science, Hegemony and Violence: A Requiem for Modernity.* New Delhi and Oxford: Oxford University Press.

National Association of Health Authorities and Trusts (1996), *Spiritual Care in the NHS: A Guide for Purchasers and Providers*. Birmingham: National Association of Health Authorities and Trusts.

Nencel, Lorraine and Pels, Peter (eds.) (1991), *Constructing Knowledge: Authority and Critique in Social Science*. London, Newbury Park, New Delhi: Sage.

Nicholson, Linda J (1990), *Feminism/Postmodernism.* New York and London: Routledge.

Nicholson, Linda (1983/93), 'Women, morality, and history,' pp 87-101 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Noddings, Nel (1984), *Caring: A Feminine Approach to Ethics and Moral Education.* Berkeley: University of California Press.

Nouwen, Henri J M (1972/79), *The Wounded Healer: Ministry in Contemporary Society.* New York, London, Toronto, Sydney, Auckland: Doubleday.

Nunner-Winkler, Gertrud (1993), 'Two moralities? A critical discussion of an ethic of care and responsibility versus an ethic of rights and justice,' pp 143-56 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Nussbaum, Martha (1990), '"Finely aware and richly responsible": literature and the moral imagination,' in *Love's Knowledge: Essays on Philosophy and Literature.* Oxford and New York: Oxford University Press.

O

Oakley, Ann (1993), *Essays on Women, Medicine and Health.* Edinburgh: Edinburgh University Press.

Oakley, Ann and Mitchell, Juliet (eds.) (1998), *Who's Afraid of Feminism: Seeing Through the Backlash.* Harmondsworth: Penguin.

Oldnall, Andrew (1996), 'A critical analysis of nursing: meeting the spiritual needs of patients,' *Journal of Advanced Nursing*, 23: 138-44.

Olesen, Virginia (1992), 'Extraordinary events and mundane ailments: the contextual dialectics of the embodied self,' pp. 205-20 in Ellis, C and Flaherty, M (eds.), *Investigating Subjectivity: Research on Lived Experience.* London, Newbury Park, New Delhi: Sage.

Ortony, Andrew (ed.) (1993), *Metaphor and Thought.* Cambridge and New York: Cambridge University Press.

Ottenberg, Simon (1990), 'Thirty years of fieldnotes: changing relationships to the text,' pp. 139-60 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

P

Pateman, Carole and Gross, Elizabeth (eds.) (1986), *Feminist Challenges: Social and Political Theory.* Sydney, London, Boston: Allen and Unwin.

Payne, Geoff (1996), 'Imagining the community: some reflections on the community study as a method,' in Lyon, ES and Busfield, J (eds.), *Methodological Imaginations.* London and Basingstoke: Macmillan.

Payne, Sheila, Horn, Sandra and Marilyn Relf (1999), *Loss and Bereavement.* Buckingham and Philadelphia: Open University Press

Payne, Sheila, Hillier, Richard, Langley-Evans, Alison and Tony Roberts (1996), 'Impact of witnessing death on hospice patients,' *Social Science and Medicine*, 43 (12): 1785-94.

Peck, M Scott (1997), *Denial of the Soul: Spiritual and Medical Perspectives on Euthanasia and Morality.* London: Simon and Schuster.

Peck, M Scott (1993), *A World Waiting to be Born: The Search for Civility.* London: Rider.

Pembrey, S (1985), 'A framework for care,' *Nursing Times*, 11 December: 47-9.

Peters-Golden, Holly (1982), 'Breast cancer: varied perceptions of social support in the illness experience,' *Social Science and Medicine*, 16: 483-91.

Picardie, Ruth, with Matt Seaton and Justine Picardie (1998), *Before I Say Goodbye.* Harmondsworth: Penguin.

Pickering, Andrew (1992), 'From science as knowledge to science as practice,' pp. 1-26 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Pickering, Andrew (ed.) (1992), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Pickering, Andrew and Stephanides, Adam (1992), 'Constructing quaternions: on the analysis of conceptual practice,' pp. 139-67 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Pierce, Christine (1991), 'Postmodernism and other skepticisms,' pp. 60-77 in Card, C (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Plath, David W (1990), 'Fieldnotes, filed notes, and the conferring of note,' pp. 371-84 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Plummer, Ken (1995), *Telling Sexual Stories: Power, Change and Social Worlds.* London and New York: Routledge.

Polanyi, Michael (1958), *Personal Knowledge: Towards a Post-Critical Philosophy.* London: Routledge and Kegan Paul.

Polkinghorne, John (1994), *Science and Christian Belief: Theological Reflections of a Bottom-up Thinker*. London: Society for Promoting Christian Knowledge.

Popper, Karl (2002, 4th edition) (1935, *Logik der Forschung*), *The Logic of Scientific Discovery*. London: Routledge.

Potter, Jonathan (1996), *Representing Reality: Discourse, Rhetoric and Social Construction*. London, Thousand Oaks, New Delhi: Sage.

Potter, Jonathan and Wetherell, Margaret (1995), 'Discourse analysis,' pp. 80-92 in Smith, JA, Harré, R and L van Langenhove (eds.), *Rethinking Methods in Psychology.* London: Sage.

Potter, Jonathan and Wetherell, Margaret (1994), 'Analysing discourse,' pp. 47-66 in Bryman, A and RG Burgess (eds.), *Analysing Qualitative Data.* London: Routledge.

Potter, Jonathan and Wetherell, Margaret (1987), *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: Sage.

Psathas, George (1995), *Conversation Analysis: The Study of Talk-in-Interaction.* London: Sage.

Puka, Bill (1993), 'The liberation of caring: a different voice for Gilligan's "different voice",' pp. 215-39 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Q

Quine, Willard van Orman (1961), *From a Logical Point of View. 9 Logico-Philosophical Essays.* New York: Harper and Row.

Quine, Willard van Orman (1960), *Word and Object.* Cambridge, MA: MIT Press.

R

Ramsay, Karen (1996), 'Emotional labour and qualitative research: how I learned not to laugh or cry in the field,' in Lyon, ES and Busfield, J (eds.), *Methodological Imaginations.* London and Basingstoke: Macmillan.

Reimer, Joanne C, Davies, Betty and Nola Martens (1991), 'Palliative care: the nurse's role in helping families through the transition of 'fading away,' *Cancer Nursing*, 14 (6): 321-7.

Reverby, Susan (1987), *Ordered to Care: The Dilemma of American Nursing, 1850-1945.* Cambridge: Cambridge University Press.

Rhodes, Lorna A (1996), 'Studying biomedicine as a cultural system,' pp. 165-80 in Sargent, CF and TM Johnson (eds.), *Medical Anthropology: Contemporary Theory and Method*, revised edition. Westport, CN and London: Praeger.

Ricoeur, Paul (1978), *The Rule of Metaphor: Multi-Disciplinary Studies of the Creation of Meaning in Language.* London: Routledge and Kegan Paul.

Riessman, Catherine Kohler (1993), *Narrative Analysis.* Newbury Park, London, New Delhi: Sage.

Riska, Elianne and Wegar, Katarina (eds.) (1993), *Gender, Work and Medicine: Women and the Medical Division of Labour.* London, Newbury Park, New Delhi: Sage.

Rius (1976/94), *Marx for Beginners.* Cambridge: Icon Books.

Rogers, Carl R (1951), *Client-centred Therapy: Its Current Practice, Implications and Theory.* London: Constable.

Rosaldo, Michelle Z (1984), 'Toward an anthropology of self and feeling,' pp. 137-57 in Schweder, RA and LeVine, RA (eds.), *Culture Theory: Essays on Mind, Self and Emotion.* Cambridge: Cambridge University Press.

Rosaldo, Michelle Z (1980a), *Knowledge and Passion: Ilongot Notions of Self and Social Life.* Cambridge: Cambridge University Press.

Rosaldo, Michelle Z (1980b), 'The use and abuse of anthropology: reflections on feminism and cross-cultural understanding,' *Signs*, 5 (3): 389-417.

Rosaldo, Renato (1993/89), *Culture and Truth: The Remaking of Social Analysis.* London: Routledge.

Rose, Gillian (2002), 'Conclusion,' pp. 253-8 in Bondi, L et al., *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research.* Lanham, Maryland and Oxford: Rowman and Littlefield.

Rose, Gillian (1997), *Love's Work.* London: Random House.

Rose, Hilary (1994), *Love, Power and Knowledge: Towards a Feminist Transformation of the Sciences.* Cambridge and Oxford: Polity Press.

Ross, Linda (1998), 'The nurse's role in spiritual care,' pp. 119-35 in Cobb, M and Robshaw, V (eds.), *The Spiritual Challenge of Health Care.* Edinburgh and London: Churchill Livingstone.

Ross, Linda A (1994), 'Spiritual aspects of nursing,' *Journal of Advanced Nursing*, 19: 439-47.

Roszak, Theodore (1969), *The Dissenting Academy.* London : Chatto and Windus.

Ruddick, Sara (1989), *Maternal Thinking: Toward a Politics of Peace.* Boston: Beacon Press.

Rumbold, Bruce (ed.) (2002), *Spirituality and Pastoral Care: Social and Pastoral Perspectives.* Melbourne, Oxford and New York: Oxford University Press.

S

Sacks, Harvey (1992; edited by Gail Jefferson), *Lectures on Conversation.* Oxford: Blackwell.

Sacks, Oliver (1991), *A Leg to Stand On.* London: Picador.

Sanders, William B (1976), 'Introduction,' pp. 1-21 in Sanders, WB (ed.), *The Sociologist as Detective: An Introduction to Research Methods.* New York: Praeger.

Sanjek, Roger (1990a), 'Preface,' pp. xi-xii in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Sanjek, Roger (1990b), 'Fire, loss, and the sorcerer's apprentice,' pp. 34-45 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Sanjek, Roger (1990c), 'A vocabulary for fieldnotes,' pp. 92-137 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Sanjek, Roger (1990d) 'The secret life of fieldnotes,' pp. 187-270 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Sanjek, Roger (1990e) 'Fieldnotes and others,' pp. 324-41 in Sanjek, R (ed.), *Fieldnotes: The Makings of Anthropology.* Ithaca and London: Cornell University Press.

Sargent, Carolyn F and Thomas M Johnson (1996) (eds.), *Medical Anthropology: Contemporary Theory and Method*, revised edition. Westport, CN and London: Praeger.

Saunders, Cicely (1990) (ed.), *Hospice and Palliative Care*. London: Edward Arnold.

Saunders, Cicely M (1984a), 'Appropriate treatment, appropriate death,' pp. 1-16 in Saunders, CM (ed. 2nd edition), *The Management of Terminal Malignant Disease*. London: Edward Arnold.

Saunders, Cicely M (1984b), 'The philosophy of terminal care,' pp. 232-41 in Saunders, CM (ed. 2nd edition), *The Management of Terminal Malignant Disease*. London: Edward Arnold.

Saunders, Cicely M (1981), 'The founding philosophy,' p. 4 in Saunders, C, Summers, DH and N Teller (eds.), *Hospice: The Living Idea.* London: Edward Arnold.

Savage, Jan (1995), *Nursing Intimacy: An Ethnographic Approach to Nurse-Patient Interaction.* London: Scutari.

Schneiders, Sandra M (1990), 'Spirituality in the academy,' pp. 15-37 in Hanson, BC (ed.), *Modern Christian Spirituality: Methodological and Historical Essays*. Atlanta, GA: Scholars Press.

Schön, Donald A (1983), *The Reflective Practitioner: How Professionals Think in Action.* London: Temple Smith.

Schweder, Richard A and LeVine, Robert A (eds.) (1984), *Culture Theory: Essays on Mind, Self and Emotion.* Cambridge: Cambridge University Press.

Schweitzer, Ann (1992), '"What do we mean by caring?" A nurse educator's reflections,' pp. 57-67 in Shogan, D (ed.), *A Reader in Feminist Ethics.* Toronto: Canadian Scholars' Press.

Scott, Joan W (1988), *Gender and the Politics of History.* New York: Columbia University Press.

Scott, Joan W (1990), 'Deconstructing equality-versus-difference: or, the uses of post-structuralist theory for feminism,' in Hirsch, M and Keller, EF (eds.), *Conflicts in Feminism.* London: Routledge.

Scott, Pam, Richards, Evelleen, and Brian Martin (1991), 'Who's a captive? Who's a victim? Response to Collins' method talk,' *Science, Technology and Human Values*, 16 (2): 252-5.

Scott, Pam, Richards, Evelleen, and Brian Martin (1990), 'Captives of controversy: the myth of the neutral social researcher in contemporary scientific controversies,' *Science, Technology and Human Values*, 15 (4): 249-51.

Sharpe, Kevin J (1984), *From Science to an Adequate Mythology.* Auckland, New Zealand: Interface Press.

Sherwin, Susan (1992), 'Ethics, "feminine" ethics and feminist ethics,' pp. 3-28 in Shogan, D (ed.), *A Reader in Feminist Ethics.* Toronto: Canadian Scholars' Press.

Sherwin, Susan (1989/92), 'Feminist and medical ethics: two different approaches to contextual ethics,' pp. 39-56 in Shogan, D (ed.), *A Reader in Feminist Ethics.* Toronto: Canadian Scholars' Press.

Sherwin, Susan (1987), 'A feminist approach to ethics,' *Resources for Feminist Research*, 16(3): 25-8.

Shiva, Vandana (1988), 'Reductionist science as epistemological violence,' pp. 232-56 in Nandy, A (ed.), *Science, Hegemony and Violence: A Requiem for Modernity.* New Delhi and Oxford: Oxford University Press.

Shogan, Debra (1992), 'Feminist ethics for strangers,' pp. 171-84 in Shogan, D (ed.), *A Reader in Feminist Ethics.* Toronto: Canadian Scholars' Press.

Shogan, D (ed.) (1992), *A Reader in Feminist Ethics*. Toronto: Canadian Scholars' Press.

Shrijvers, Joke (1991), 'Dialectics of a dialogical ideal: studying down, studying sideways and studying up,' pp. 162-79 in Nencel, L and Pels, P (eds.), *Constructing Knowledge: Authority and Critique in Social Science*. London, Newbury Park, New Delhi: Sage.

Simpson, Michael A (1987), *Dying, Death and Grief: A Critical Bibliography*. Pittsburgh, PA: University of Pittsburgh Press.

Simpson, Michael A (1979), *Dying, Death and Grief: A Critical Bibliography*. New York: Plenum.

Singleton, Vicky (1996), 'Feminism, sociology of scientific knowledge and postmodernism: politics, theory and me,' *Social Studies of Science*, 26 (2): 445-468.

Smith, Dorothy E (1977/87), *The Everyday World as Problematic: A Feminist Sociology*. Milton Keynes: Open University Press.

Sontag, Susan (1989), *AIDS and its Metaphors*. London: Allen Lane.

Sontag, Susan (1979), *Illness as Metaphor*. London: Allen Lane.

Spelman, Elizabeth V (1991), 'The virtue of feeling and the feeling of virtue,' pp. 213-32 in Card, C (ed.), *Feminist Ethics*. Kansas: University Press of Kansas.

Spivak, Gayatri Chakravorty (1988), *In Other Worlds: Essays in Cultural Politics*. New York and London: Routledge.

Spradley, James P (1980), *Participant Observation*. New York: Holt, Rinehart and Winston.

Spradley, James P (1979), *The Ethnographic Interview*. New York: Holt, Rinehart and Wilson.

Stacey, Margaret (1988), *The Sociology of Health and Healing: A Textbook*. London: Unwin Hyman.

Stanley, Liz and Sue Wise (1993), *Breaking Out Again: Feminist Ontology and Epistemology*. London: Routledge.

Stanworth, Rachel (1997), 'Spirituality, language and depth of reality,' *International Journal of Palliative Nursing*, 3 (1): 19-22.

Star, Susan L (1994), 'Leaks of experience: being human is articulating the cracks between,' unpublished draft, University of Illinois.

Star, Susan L (1991), 'Power, technology and the phenomenology of conventions: on being allergic to onions,' pp 26-56 in Law, J (ed.), *Power, Technology and the Modern World.* Oxford: Blackwell

Steier, Frederick (1991) (ed.), *Research and Reflexivity.* London, Newbury Park, New Delhi: Sage.

Stoddard, Sandol (1978), *The Hospice Movement: A Better Way of Caring for the Dying.* London: Jonathan Cape.

Stoll, Ruth I (1989), 'The essence of spirituality,' pp. 4-23 in Carson, VB (ed.) *Spiritual Dimensions of Nursing Practice.* Philadelphia and London: WB Saunders.

Stoter, David (1995), *Spiritual Aspects of Health Care.* London: Mosby.

Strathern, Marilyn (1991), *Partial Connections.* Savage, M.D.: Rowman and Littlefield.

Strathern, Marilyn (1987), 'The limits of auto-anthropology,' pp. 16-37 in Jackson, A (ed.), *Anthropology at Home.* Association of Anthropologists, London and New York: Tavistock.

Strauss, Anselm, Fagerhaugh, Shizuko, Suczek, Barbara and Carolyn Wiener (1985), *Social Organization of Medical Work.* Chicago and London: University of Chicago Press.

Strauss, Susan (2000), 'Locating yoga: ethnography and transnational practice,' pp. 162-94 in Amit, V (ed.) *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

Stump, David J (1996), 'From epistemology and metaphysics to concrete connections,' pp. 255-85 in Galison, P and Stump DJ (eds.) , *The Disunity of Science: Boundaries, Contexts and Power.* Stanford, CA: Stanford University Press.

Sumaya-Smith, Isabel (1995), 'Caregiver/resident relationships: surrogate family bonds and surrogate grieving in a skilled nursing facility,' *Journal of Advanced Nursing*, 21 (3): 447-51.

Svoboda, Robert E (1992), *Ayurveda: Life, Health and Longevity.* London: Penguin.

Swire, Nina and George, Rob (1997), 'The "egg" model,' paper presented at Spiritual Dimensions of Health Care conference, British Holistic Medical Association, London, October 1997.

T

Tambiah, Stanley J (1990), *Magic, Science, Religion and the Scope of Rationality.* Cambridge: Cambridge University Press.

Tanesini, Alessandra (1996), 'Whose language?' pp 353-66, in Garry, A and Pearsall, M (eds.) *Women, Knowledge and Reality: Explorations in Feminist Philosophy.*

Taylor, Elizabeth Johnston, Highfield, Martha and Madalon Amenta (1994), 'Attitudes and beliefs regarding spiritual care: a survey of cancer nurses,' *Cancer Nursing*, 17 (6): 479-87.

Thatcher, Margaret (1985), 'Facing the new challenge,' pp. 213-7 in Ungerson, C (ed.), *Women And Social Policy: A Reader.* London: Macmillan.

Tilley, Stephen (1995), *Negotiating Realities: Making Sense of Interaction Between Patients Diagnosed as Neurotic and Nurses.* Aldershot: Avebury.

Tisdale, Sallie (1987), *Harvest Moon: Portrait of a Nursing Home.* New York: Henry Holt.

Torrance, Thomas F (1985), *Reality and Scientific Theology.* Edinburgh: Scottish Academic Press.

Torrie, Margaret (1987), *My Years with Cruse.* Richmond Cruse House, London: Cruse.

Traweek, Sharon (1992), 'Border crossings: narrative strategies in science studies and among physicists in Tsukuba Science City, Japan,' pp. 429-65 in Pickering, A (ed.), *Science as Practice and Culture.* Chicago and London: University of Chicago Press.

Traweek, Sharon (1988), *Beamtimes and Lifetimes: The World of High Energy Physicists.* Cambridge, MA and London: Harvard University Press.

Treweek, Geraldine Lee (1996), 'Emotion work, order, and emotional power in care assistant work,' pp. 115-32 in James, V and Gabe, J (eds.), *Health and the Sociology of Emotions.* Oxford and Cambridge, MA: Blackwell.

Tronto, Joan C (1987/93), 'Beyond gender difference to a theory of care,' pp. 240-57 in Larrabee, M (ed.), *An Ethic of Care: Feminist and Interdisciplinary Perspectives.* New York and London: Routledge.

Tronto, Joan C (1993), *Moral Boundaries: A Political Argument for an Ethic of Care.* New York and London: Routledge.

Tschudin, Verena (1992; 2nd revised edition), *Ethics in Nursing: The Caring Relationship*. Oxford: Butterworth-Heinemann.

Tsing, Anna Lowenhaupt (1993), *In the Realm of the Diamond Queen.* Princeton, NJ: Princeton University Press.

Turner, Bryan S (2nd edition, 1996), *The Body and Society.* London, Thousand Oaks, New Delhi: Sage.

Turner, Bryan S (1987), *Medical Power and Social Knowledge.* London, Beverley Hills, New Delhi: Sage.

Twycross, Robert (2003, 4th edition), *Introducing Palliative Care*. Oxford: Radcliffe Medical Press.

Twycross, Robert G (1984), 'Relief of pain,' pp. 64-90 in Saunders, CM (ed. 2nd edition), *The Management of Terminal Malignant Disease*. London: Edward Arnold.

U

Ungerson, Clare (1987), *Policy is Personal: Sex, Gender, and Informal Care*. London: Tavistock.

Ungerson, Clare (1985a), 'Introduction: women and the informal and voluntary sector of the social services,' pp. 209-12 in Ungerson, C (ed.), *Women And Social Policy: A Reader*. London: Macmillan.

Ungerson, Clare (1985b), 'Introduction: women and the personal social services,' pp. 185-9 in Ungerson, C (ed.), *Women And Social Policy: A Reader*. London: Macmillan.

University of Edinburgh (1997), *A Code of Practice for Supervisors and Research Students*. Edinburgh: University of Edinburgh.

V

Van Maanen, John (1988), *Tales of the Field: On Writing Ethnography.* Chicago and London: University of Chicago Press.

Vetterling-Braggin, Mary, Elliston, Frederick A and Jane English (1978), *Feminism and Philosophy*. Towota, NJ: Littlefield, Adams.

Visvanathan, Shiv (1997), *A Carnival for Science: Essays on Science, Technology and Development*. Oxford and New Delhi: Oxford University Press.

Visweswaran, Kamala (1994), *Fictions of Feminist Ethnography.* Minneapolis: University of Minnesota Press.

Vivat, Bella (2002), 'Situated ethics and feminist ethnography in a West of Scotland hospice,' pp. 236-52 in Bondi, L et al, *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research.* Lanham, Maryland and Oxford: Rowman and Littlefield.

W

Walby, Sylvia (1997), *Gender Transformations.* London and New York: Routledge.

Walker, Alice (1983), *In Search of Our Mothers' Gardens.* New York: Harcourt, Brace, Jovanovich.

Walter, James J and Shannon, Thomas A (eds.) (1990), *Quality of Life: The New Medical Dilemma.* New York: Paulist Press.

Walter, Tony (1997), 'The ideology and organization of spiritual care: three approaches,' *Palliative Medicine*, 11: 21-30.

Walter, Tony (1994), *The Revival of Death.* London: Routledge.

Ward, Janie Victoria (1988), 'Urban adolescents' conceptions of violence,' in Gilligan, C, Ward, JV, Taylor, JMcL with B Bardige (eds.), *Mapping the Moral Domain: A Contribution of Women's Thinking to Psychological Theory and Education.* Cambridge, MA and London: Harvard University Press.

Warren, Kay B and Bourque, Susan C (1991), 'Women, technology and international development ideologies: analyzing feminist voices,' pp. 278-311 in di Leonardo, M (ed.), *Gender at the Crossroads of Knowledge: Feminist Anthropology in the Postmodern Era.* Berkeley, LA, Oxford: University of California Press.

Watson, Graham (1991), 'Rewriting culture,' pp. 73-92 in RG Fox (ed.), *Recapturing Anthropology: Working in the Present.* Santa Fe: School of American Research Press.

Waugh, Linda (1992), 'Spiritual aspects of nursing: a descriptive study of nurses' perceptions,' unpublished PhD thesis, Queen Margaret College, Edinburgh.

Weil, Simone (1959), *Waiting on God.* London: Collins.

White, Gillian (2000), 'An inquiry into the concepts of spirituality and spiritual care,' *International Journal of Palliative Nursing,* 6: 479-84.

White, Roger M (1996), *The Structure of Metaphor: The Way the Language of Metaphor Works*. Cambridge, MA: Blackwell.

Wilkinson, Sue and Kitzinger, Celia (1995), 'Introduction,' pp. 1-9 in Wilkinson, S and C Kitzinger (eds.), *Feminism and Discourse: Psychological Perspectives*. London, Thousand Oaks, New Delhi: Sage

Wilkinson, Sue and Kitzinger, Celia (eds.) (1995), *Feminism and Discourse: Psychological Perspectives*. London, Thousand Oaks, New Delhi: Sage

Williams, Simon J and Bendelow, Gillian (1996), 'Emotions, health and illness,' pp. 25-53 in James, V and Gabe, J (eds.), *Health and the Sociology of Emotions.* Oxford and Cambridge, MA: Blackwell.

Winch, Peter (1990; 2nd edition), *The Idea of a Social Science, and its Relation to Philosophy*. London: Routledge and Kegan Paul.

Winner, Langdon (1986/89), *The Whale and the Reactor: A Search for Limits in an Age of High Technology*. Chicago and London: University of Chicago Press.

Wittgenstein, Ludwig (1958, 2nd edition, translated by GEM Anscombe), *Philosophical Investigations*. Oxford: Basil Blackwell.

Wolmark, Jenny (1994), *Aliens and Others: Science Fiction, Feminism and Postmodernism*. Hemel Hempstead: Harvester Wheatsheaf.

Wolcott, Harry F (1999), *Ethnography: The Art of Seeing.* Walnut Cree, CA, London and New Delhi: Sage.

Wolcott, Harry F (1990), *Writing Up Qualitative Research.* Newbury Park, London and New Delhi: Sage.

Wolpert, Lewis (1992), *The Unnatural Nature of Science*. London: Faber and Faber.

Wood, Linda A and Rolf O Kroger (2000), *Doing Discourse Analysis: Methods for Studying Action in Talk and Text*. Thousand Oaks, London, New Delhi: Sage.

Woolgar, Steve (1992), 'Some remarks about positionism: a reply to Collins and Yearley,' pp. 327-42 in Pickering, A (ed.), *Science as Practice and Culture*. Chicago and London: University of Chicago Press.

Woolgar, Steve (1988), *Science: The Very Idea!* London: Tavistock.

Woolgar, Steve (1988) (ed.), *Knowledge and Reflexivity: New Frontiers in the Sociology of Knowledge*. London, Newbury Park, Beverly Hills, New Delhi: Sage.

Wortman, Camille B (1983), 'Social support and the cancer patient: conceptual and methodological issues,' *Cancer*, 53 (10): 2339-62: 2347-8.

Wright, Stephen G and Sayre-Adams, Jean (2000), *Sacred Space: Right Relationship and Spirituality in Healthcare.* London: Churchill Livingstone.

Wulff, Helena (2000), 'Access to a closed world: methods for a multilocale study on ballet as a career,' pp. 147-61 in Amit, V (ed.) *Constructing the Field: Ethnographic Fieldwork in the Contemporary World.* London and New York: Routledge.

Wyndham, John (1974), *Jizzle*. London: New England Library.

Wynne, Brian (1996), 'SSK's identity parade: signing-up, off-and-on,' *Social Studies of Science*, 26 (2): 357-392.

Wynne, Brian (1988), 'Unruly technology: practical rules, impractical discourses and public understanding,' *Social Studies of Science*, 18 (1): 147-67.

X

Y

Yamada, Yoko, Kato, Yoshinobu, Ito, Tetuji and Yuichi Toda (2002), 'The spatial representations of this world and the next world in Japanese, Vietnamese, British and French drawings,' paper presented at The Social Context of Death, Dying and Disposal 6th International Conference, York, September 2002.

Young, Elizabeth H and Lee, Raymond H (1996), 'Fieldworker feelings as data,' pp. 97-113 in James, V and Gabe, J (eds.), *Health and the Sociology of Emotions.* Oxford and Cambridge, MA: Blackwell.

Z

Ziman, John (1984/88), *An Introduction to Science Studies: The Philosophical and Social Aspects of Science and Technology.* Cambridge: Cambridge University Press.

Zola, Irving K (1983), *Socio-Medical Inquiries: Recollections, Reflections, and Reconsiderations*. Philadelphia: Temple University Press.

- APPENDIX I -

REQUEST FOR ACCESS

The Administrative Director
St Z's Hospice

8 December 1997

Dear Madam/Sir

I am a student in the Science Studies Unit of the University of Edinburgh, and have been a volunteer at a hospice in Edinburgh for the past eighteen months. I am currently beginning my second year of a PhD in which I am conducting research into the provision of spiritual care for dying and bereaved people. As a significant component of my research I hope to explore spiritual caring within the hospice movement, looking at the parts played by all those within hospice, but with a particular focus on the role of volunteers.

Through this research I hope to gain greater insight into how spiritual care is provided and into the factors which affect its provision. I also hope to contribute both to the literature on spiritual care, and to the limited literature on the relation between training and experience in the provision of care.

I am writing to you to request an appointment to discuss whether it would be possible for me to carry out my proposed research in St Z's Hospice. I would be grateful for the opportunity to meet with you to explain and discuss my project further, and your advice and suggestions would assist me in fine-tuning my research plan.

My planned study is descriptive, and would be two-fold: observing hospice practice in different areas and conducting individual, informal interviews with members of staff and volunteers. I would hope to observe suitable locations within the hospice, which I would expect to determine and agree with you during our discussion. Flowing from my observations I would identify the people whom I wished to interview in more depth and I would expect to arrange this with you and with them as the situation arose.

If you require any further information, please contact me at the above address, or on 650 2451, or contact my supervisors: Dr Liz Bondi (650 2529) or Dr Steve Tilley (650 3881).

Yours faithfully

Bella Vivat
cc: Dr Liz Bondi; Dr Steve Tilley

- APPENDIX II -

RESEARCH INFORMATION SHEET

Dear

I am interested in finding out how different hospice workers provide spiritual care for hospice patients, and how training and experience contribute to the provision of this care. In order to do this, I will, firstly, be spending time in various parts of the hospice, observing its activities at first hand. Secondly, I would like to ask people to tell me about how they came to work in hospice, what they do in hospice, and what they think about what they do.

I would like your help in this research. This would involve you setting some time aside at your convenience to discuss your activities in the hospice with me. Whatever you choose to tell me will be strictly confidential. If possible I would like to record our conversations on tape, or in note form if you do not wish me to use a tape recorder. I will not repeat anything you say to me to anyone in the hospice and I will ensure that you cannot be identified in anything which I write about my study. I will keep any tapes in a secure place and I will erase them when I have finished writing my research reports.

If my work results in material for publication, I will ensure that no participant can be identified from its content. Further, if there were any material which you specifically did not wish me to include in published form, I would respect that wish.

The kind of research I want to do depends upon your help and cooperation, and I would be happy to answer any questions you have about it. You are entirely free to agree or not to agree to take part in this research. If you agree to take part, please read and sign the accompanying consent form. You may withdraw your agreement, if given, at any time.

Yours sincerely

Bella Vivat, PhD Student, University of Edinburgh

- APPENDIX III -

CONSENT FORM

TITLE OF STUDY: Spirituality and spiritual care in the hospice movement

NAME OF RESEARCHER: Bella Vivat

ADDRESS AND TELEPHONE: Graduate School in the Social Sciences, University of Edinburgh, High School Yards, Edinburgh EH1 1LZ
Tel: 0131-650 2451

FURTHER INFORMATION IS AVAILABLE FROM: myself or my supervisors, Dr Liz Bondi (0131-650 2529) or Dr Steve Tilley (0131-650 3881)

- I have read the letter outlining the aims and plan of this research. I have had the opportunity to ask questions about it and I understand its content.
- I agree to participate in conversational interviews for the purposes of the study, and **give*/do not give*** my permission for them to be tape recorded.
- I understand that I am under no obligation to take part in this study and that I have the right to withdraw from it at any stage.
- I understand that this information is confidential and that all reasonable measures will be taken by the researcher to ensure that individual participants cannot be identified in any report on the study.

*** please delete as appropriate**

Signature of interviewee.....

Name (please print).....

Signature of researcher.....

Date.....

- APPENDIX IV -

CODES FOR AND BRIEF BIOGRAPHIES OF WORKERS

Occupational codes

Vol: volunteer
StN: student nurse
SN: staff nurse
AN: auxiliary nurse
Sr (sister): nun
Fr (father): priest
Rev: Reverend
PT: physiotherapist
OT: occupational therapist
SW: social worker
HCC: home care coordinator
DCC: day care coordinator
PCC: pastoral care coordinator
Dr: doctor

People with whom I taped interviews

SN 2: staff nurse on St E's; in her late 30s with teenage children, had given up nursing when her first child was born, had returned to nursing a few years prior to my fieldwork

SN 3: staff nurse on St P's; married; in her early 20s; had done part of her student nurse training in St Z's, came there when qualified, worked on St E's first, and later moved to St P's

SN 4: sister on St E's; in her late 30s, married with two young children

Dr 5: male doctor; in his mid-late 40s, medical director (senior consultant). The only consultant for the first 12 years of St Z's. His specialty was anaesthesiology, and his interest in chronic pain related to this was what had brought him into hospice care

SN 6: sister on St P's

SN 7: sister on St E's; in her late 30s, married with two young children

Sr (Sister) 8: nursing director/matron; nun all her adult life; in her early 50s

PT 9: physiotherapist; in her early 40s

SW 10: senior social worker; in her late 40s, ran the drop-in for bereaved children

HCC 11: in her mid-late 40s; married with two adult children; had worked on St P's for about 10 years, the last few as sister. She left to become a Macmillan nurse about two years prior to my fieldwork; returned after a year to set up and run the new hospice home care service. She became the deputy matron after Sr 13 returned to London

SW 12: social workers; single woman in her late 50s; ex-hospital social worker

Sr (Sister) 13: a nun in her mid-40s, who had been a nun since her early 20s. When I began my fieldwork she was the deputy matron at St Z's; she left towards the end of my fieldwork and returned to the London hospice run by the same order

DCC 14: day care coordinator; in her mid-30s, married with no children; trained as occupational therapist

SN 16: part-time senior staff nurse on St P's; mid 40s with two adult children, had left nursing to look after her children full time when they were small, and had returned to nursing relatively recently, when she had wanted to begin working in palliative care, although she said she didn't really know why

SN 17: staff nurse on St P's; in her mid 20s, one of a big Catholic family (8 children). She had first come to St Z's as a nursing student, and returned when she qualified, had been working on St P's for a few years by the time I began my fieldwork

Fr (Father) 18: Irish Catholic priest in his early 40s; visited Catholic patients on the wards and held mass in the chapel

Rev 19: female Church of Scotland minister in her late 40s; on the St Z's management board and gave a weekly Church of Scotland service in the chapel

Dr 21: "Dr Peter" male consultant, married, in his mid-late 30s; appointed as second consultant in September 1999, having previously worked as a registrar on a Palliative Care Team in a city hospital. One of the few workers in St Z's who had planned to end up in hospice care (rather than falling into it by accident). He was an Episcopalian Christian, who said he was "slightly evangelical." After his appointment, 10 of the 20 beds on St E's were allocated to palliative care beds (for which he was responsible), the 10 beds on St P's were still palliative care (Dr 5's beds), but eventually St E's beds would be all palliative care and St P's would be elderly care

SN 23: sister on St P's

PCC 24: pastoral care coordinator

Other workers mentioned

SN 25: night sister on St P's, had been a nun, but left and got married

AN 26: auxiliary nurse on St E's; in her early 20s

OT 27: assistant in day care, occupational therapist by training; in her late 40s

SN 28: staff nurse on St P's; in her mid 40s

SN 29: staff nurse on St P's; in her mid 40s

AN 30: an auxiliary nurse on St P's; in her early 50s

OT 31: a woman in her early 30s who had run the activities for the elderly patients in the activity room on St E's, and began helping with the day care after it moved there

Vol A: day care volunteer in her late 40s.

Vol B: day care volunteer in her early 50s.

Vol T: day care volunteer in her late 50s; had been a day care patient

- APPENDIX V -

TRANSCRIPT NOTATION

(.)	a brief, but noticeable, pause
(..)	a slightly longer pause
(.....)	a significantly long pause
bu-	a dash indicates a sharp cutoff of speech
italics	italicised text indicates emphasis
italics	italicised and underlined text indicates slightly stronger emphasis
bold	bold text indicates very strong emphasis
CAPITALS	capitals indicate talk that is noticeably louder than surrounding talk
°quiet°	degree signs indicate talk that is noticeably quieter than surrounding talk
°°quiet°°	doubled degree signs indicate extremely quiet talk
>fast< <slow>	"less than" and "greater than" signs indicate talk that is noticeably faster or slower than surrounding talk
me: you see you say it's	[**17**: it's (..) talk on the same line as other talk beginning with a square bracket indicates overlapping/simultaneous talk
[**me**: mmhm	indented talk on a new line beginning with a square bracket indicates talk which occurs during ongoing talk but does not interrupt that talk
ho:me	a colon indicates lengthening of the preceding sound or syllable
↑word	an up arrow indicates noticeably rising intonation in the talk that follows

↓word	a down arrow indicates noticeably falling intonation in the talk that follows
?	a question mark indicates a rising inflection
!	an exclamation mark indicates an animated or emphatic tone
wo(h)rd	an "h" in parentheses indicates laughter within a word
doesnae	modified spelling is used to suggest pronunciation
(?)	a question mark in single parentheses indicates unclear material, which I have been unable to guess at
(?word)	words in single parentheses prefixed by a question mark indicate my best guess at unclear material
(word)	words in single parentheses indicate where I have made a guess at unclear material which I think is extremely likely to be accurate
((laughs)) or ((phone rings))	double parentheses indicate descriptions of non-speech sounds other features of the talk or the situation
[*a local pub*]	square brackets and italics enclose contextual or explanatory information
[...]	square brackets and horizontal ellipses indicate talk omitted from the data cited
->	a horizontal arrow in the left margin indicates an utterance discussed in the text

Speakers are identified by letters, indicating their professional role, and a number (which, for workers 1-24, relates to their interview number). Lines are numbered.

I have slightly adapted this system of notation from the notation derived from Gail Jefferson's system by Linda Wood and Rolf Kroger.[1]

---

[1] Gail Jefferson (1984), 'On the organization of laughter in talk about troubles,' in JM Atkinson and J Heritage (eds.), *Structures of Social Action: Studies in Conversation Analysis*. Cambridge: Cambridge University Press: 346-69, cited in Linda A Wood and Rolf O Kroger (2000), *Doing Discourse Analysis: Methods for Studying Action in Talk and Text*. Thousand Oaks, London, New Delhi: Sage: 193-4. See also Derek Edwards (1997), *Discourse and Cognition*. London, Thousand Oaks, New Delhi: Sage.

Subjectivities, Knowledges, and Feminist Geographies

The Subjects and Ethics of Social Research

Liz Bondi, Hannah Avis, Ruth Bankey, Amanda Bingley, Joyce Davidson, Rosaleen Duffy, Victoria Ingrid Einagel, Anja-Maaike Green, Lynda Johnston, Susan Lilley, Carina Listerborn, Shonagh McEwan, Mona Marshy, Niamh O'Connor, Gillian Rose, Bella Vivat, and Nichola Wood

ROWMAN & LITTLEFIELD PUBLISHERS, INC.
Lanham • Boulder • New York • Oxford

ROWMAN & LITTLEFIELD PUBLISHERS, INC.

Published in the United States of America
by Rowman & Littlefield Publishers, Inc.
An Imprint of the Rowman & Littlefield Publishing Group
4720 Boston Way, Lanham, Maryland 20706
www.rowmanlittlefield.com

12 Hid's Copse Road
Cumnor Hill, Oxford OX2 9JJ, England

British Library Cataloguing in Publication Information Available

Library of Congress Cataloging-in-Publication Data

Subjectivities, knowledges, and feminist geographies: the subjects and ethics of social research / Liz Bondi . . . [et al.].
p. cm.
Includes bibliographical references (p.) and index.
ISBN 0-7425-1561-3 (cloth : alk. paper) — 0-7425-1562-1 (pbk. : alk. paper)
1. Feminist theory. 2. Feminist geography. 3. Spatial behavior. 4. Subjectivity. I. Bondi, L. (Liz)
HQ1190 .S82 2002
305.42'01—dc21

2002001880

Printed in the United States of America

™ The paper used in this publication meets the minimum requirements of American National Standard for Information Sciences—Permanence of Paper for Printed Library Materials, ANSI/NISO Z39.48-1992.

Contents

Acknowledgments vii

Introduction 1
Liz Bondi

Part I Embodiment, Emotions, and Subjectivities

1 All in the Mind?: Women, Agoraphobia, and the Subject of Self-Help 15
Joyce Davidson

2 Understanding the Geography of Women's Fear: Toward a Reconceptualization of Fear and Space 34
Carina Listerborn

3 Embodying Agoraphobia: Rethinking Geographies of Women's Fear 44
Ruth Bankey

4 "Once More with Feeling": Putting Emotion into Geographies of Music 57
Nichola Wood

Part II Dualisms, Bodies, and Subjectivities

5 Borderline Bodies 75
Lynda Johnston

6 Crossing Boundaries: Gendered Spaces and Bodies in Golf 90
Shonagh McEwan

7 Talking with the Magician's Apprentice: Fleshing Out GIS Users 106
Susan Lilley

15

Situated Ethics and Feminist Ethnography in a West of Scotland Hospice

Bella Vivat

Between February 1998 and April 1999 I conducted an ethnographic study of St. Z's, a hospice in the west of Scotland. Building on feminist and postcolonial perspectives on the social shaping of knowledge (or, as Sandra Harding [1998] puts it, the co-evolution of cultures/societies and knowledges), I was seeking to investigate the claim of hospices to provide "total care" and the relation between this and allopathic medical practice, including the increased medicalization of hospices over the past thirty years. In particular, I sought to explore the spiritual aspects of hospice care.

Before embarking on my fieldwork, I had considered ethical issues that were likely to arise primarily in terms of establishing a framework for negotiating informed consent. But, as my fieldwork progressed, I became aware of the pervasiveness and relevance of questions about ethics to my research questions and my research practice. This chapter explores some of these issues, arguing that ethics are situated and, therefore, advocating a contextualized and situated approach to ethical research practice. In the remainder of this section I introduce the context informing my argument. I then proceed to outline the ideas and debates on which I have drawn to make sense of the numerous ethical concerns I engaged with during my time in St. Z's, and then end the chapter with a discussion of some of these concerns, focusing particularly on ethical issues that arose in the relationship between myself as a researcher and the people in my research site.

On one level it is obvious that ethical questions were present in my research from the beginning, since in daily life we are constantly making decisions, to a more or less conscious extent, concerning which actions are right or wrong. But, on another level, I have had to make specific ethical choices throughout my research, that is, make decisions concerning what I felt I should or should not do, and these decisions have in turn shaped the directions I followed. For example, ethical issues arose when

I was choosing a hospice in which to do my fieldwork and when I was considering whether to conduct tape-recorded interviews with hospice patients. I was aware that I thought about these choices in terms of right and wrong, but I had not consciously thought through, nor theorized, my own ethical position.

As my fieldwork progressed, I also became aware of disagreements between people in the hospice, which they often framed in ethical terms (that is, using words such as "should," "ought," "right/wrong," "fair/unfair"). Some of these disagreements were openly discussed. So, for example, there was some debate over staff interactions with, and attitudes toward, patients, especially when workers perceived particular patients as being "difficult to get on with." There were also less open tensions within hospice workers' relationships, especially between managers and staff, and also concerning how relationships among staff affected relationships between staff and patients. Some hospice workers explicitly referred to what they perceived as contradictions between managers' professed spiritual beliefs and their relationships with workers.

As a result of my increasing awareness of the tensions between people in the hospice, I began to consider how ethical issues arose in the relations between the people I was studying and their differing perceptions of the right and wrong ways of behaving toward others, particularly coworkers. I also began to work out the characteristics of my own moral position, to make sense of my own discomfort with the lack of fit of canonical ethical theories to my own ethical beliefs, to attempt to understand some of the disagreements between people in the hospice, and to link these to wider questions of knowledge and subjectivity.

My thinking is informed by feminist and postcolonial philosophies of knowledge, which, through concepts such as "situated knowledge" (Haraway 1988), "strong objectivity" (Harding 1986) and "neo-rationality" (Lazreg 1994) attempt to dislodge "pure" reason from its canonical status as the sole arbiter of what counts as knowledge (and which people count as knowers) without rejecting it completely. Linked to this, Susan Hekman (1995: 69) argues that "what we know and who we are cannot be neatly separated," and other feminist philosophers of knowledge such as Lorraine Code (1991) and Patricia Hill Collins (1996) argue that epistemology, subjectivity, agency, and morality are interwoven. Some discussions of spirituality, including Daphne Hampson's (1996) account of post-Christian morality, and Steve Wright and Jean Sayre-Adams's (2000) analysis of spirituality in health care as a "right relation" between caregivers and those for whom they care, similarly link subjectivity, morality, and spirituality.

In the context of these ideas this chapter examines the relevance of Carol Gilligan's work to my study. Gilligan's "ethic of care" (Gilligan 1993) is often equated with feminist ethics, but feminist ethics addresses many themes, of which the ethic of care is only one. Indeed, many feminist ethicists argue against the version of the ethic of care that is most prominent. Further, although this version of the ethic of care is based on the work of Gilligan, I will argue that it is an incomplete representation of her position. In the next section of this chapter I outline my understanding of Gilligan's work and argue for a shift away from her opposed "ethic

of care" and "ethic of justice" to the notions of "situated ethics" and "detached ethics." In the light of this shift, I then consider my findings and experiences at St. Z's.

FROM AN ETHIC OF CARE TO SITUATED ETHICS

Carol Gilligan's (1993) landmark text *In a Different Voice* was conceived and written in response to Lawrence Kohlberg's (1981) argument that "mature," "advanced," or "post-conventional" morality is characterized by abstraction and detachment from concrete situations in favor of producing generalized rules and laws, and that women tend not to reach this stage of moral development. By contrast Gilligan argued that there are two different moralities and that these are gendered, such that men tend to adhere to what she calls an ethic of justice, or "morality of rights," which has fairness and equality as its primary values, while women tend to adhere to what she calls an ethic of care, or "morality of responsibility," which has inclusion and protection from harm as its primary values.

Echoing Kohlberg, Gilligan claims that both of these moralities have three levels: pre-conventional, at which the agent is self-centered; conventional, at which the agent conforms to social norms; and post-conventional, at which the agent questions and reflects upon these norms. At Kohlberg's post-conventional level of morality, agents produce abstract, detached ethical principles; but Gilligan argues that, since social norms differ for men and women, women at the post-conventional level of her ethic of care do not seek to detach themselves from relationships, and so women's post-conventional morality can appear conventional in Kohlberg's terms.[1]

Gertrud Nunner-Winkler (1993) argues that the difference between Gilligan's two moralities is one of orientation rather than of content, and I think that, despite her claim that the distinction between her two moralities lies in their primary values, Gilligan's work actually suggests that the values of inclusion and protection from harm do not replace, but rather coexist with values of equality and fairness. Similarly her ethic of justice may also include values associated with care. Indeed, Gilligan (1993: 74) explicitly states that at the post-conventional level of her ethic of care, "Care becomes the self-chosen principle of a judgement that remains psychological in concern with relationships and response but *becomes universal in its condemnation of exploitation and hurt*" (my emphasis). Thus, I would argue that this morality contextualizes and amplifies, rather than replaces, the principles of fairness and justice, so that the post-conventional level of Gilligan's ethic of care is both universal (condemning exploitation) and particular (concerned with context). In other words, at the post-conventional level of Gilligan's ethic of care, the agent applies abstract, universal rules contextually, emphasizing and seeking to preserve relationships between people.

Following from this, for Gilligan, the resolution of Kohlberg's "Heinz dilemma" (whether Heinz should steal a drug or allow his wife to die) is achieved for boys by establishing a hierarchy between wrongs, and for girls by weighing up the social and

personal consequences of each wrong for the people involved. That is, for girls, as for boys, both stealing and allowing someone to die are (absolutely/universally) wrong, but when girls are asked to choose between these two actions, they attend to the context within which the choice is being made, rather than seeking to produce an absolute rule that applies regardless of the situation.

Nunner-Winkler claims that Kohlberg's "correct" solution to his Heinz dilemma demonstrates that his claim that his post-conventional morality is detached does not hold, but rather shows that a detached morality is impossible. It is not irrelevant that it is Heinz's wife around whom the dilemma revolves, since the solution to the dilemma is not that one should steal in order to prevent *all* people from dying, only a particular person. Thus, even at the post-conventional level of Kohlberg's ethic of justice, the agent pays attention to the situation. The difference is that this approach claims *not* to consider the context in which the ethical choice is made and extends this context-free claim to suggest that contextual judgments are flawed, immature, and inferior because of their subjective character.

In summary, the distinction between Gilligan's "ethic of care" and "ethic of justice" lies in how the agent applies universal ethical rules, that is, whether or not the agent explicitly acknowledges and takes account of the situation in which the moral choice is to be made, or claims it is irrelevant. Thus, Gilligan's ethic of care is overtly relational, as opposed to her ethic of justice, which claims to be individualistic, isolated, and detached from a situation or relationship.

Gilligan's works subsequent to *In a Different Voice* (Brown and Gilligan 1992; Gilligan et al. 1988) are richer, more complex, and more subtle. In contrast to her initial assumption of a unidirectional movement through the levels of her ethic of care, from pre-conventional through conventional to post-conventional, her later work shows women progressing and regressing between these levels. In her collaborative work with Lyn Mikel Brown (Brown and Gilligan 1992), they highlight the struggles and tensions adolescent girls experience in relation to the self-sacrificial nature of the conventional level of morality (thus also in relation to the conventional female self-sacrificial role), observing these girls' sense of having to "give themselves up" by prioritizing care for others over care for themselves, in order to (continue to) have relationships.

Gilligan has had a wide influence, and she has also been widely criticized. Some criticisms do not apply to the whole of her ethic of care, but rather to developments of its conventional level by writers such as Nel Noddings (1984) and Sara Ruddick (1989). So, Noddings argues that the ethic of care is modeled on *agape* in the mother-child relationship, that is, unidirectional caring from the caregiver (mother) to the cared-for (child). This is, however, only equivalent to the conventional level of Gilligan's ethic of care; at her post-conventional level the agent reflects on and rejects the inequity of this conventional level of morality. Other criticisms of Gilligan have greater validity, in particular those that challenge her methodology, her sweeping generalizations about "women," and the dichotomies she sets up. Linked to this, her interchangeable use of terms, such as morality and ethics, responsibility, and care, is also confusing and problematic.

Nevertheless, I agree with commentators such as Alison Jaggar (1991) and Michele Moody-Adams (1991), who argue that, even if Gilligan's work is flawed and overgeneralized, it remains extremely important. By suggesting that there is a way of reasoning ethically, which is profoundly different from that prized by the canonical tradition, and that, contra the canonical tradition, this other way of reasoning is neither immature nor inferior, Gilligan brought to light questions about morality in fundamental ways, and I have used Gilligan's work as my starting point. However, there are two important ways in which my analysis departs from Gilligan's framework. The first concerns conflicts among women and the second concerns a shift in terminology related to the question of dichotomies.

First, Brown and Gilligan's (1992) analysis of moral reasoning by adolescent girls emphasizes that girls allow rules to be broken or will abandon a game rather than disagree with one another or exclude someone. They also highlight how girls silence themselves in order to maintain relationships with other girls who would ostracize them if they did not conform. However, they fail to discuss the ostracizing of nonconformists from the perspective of those ostracizing or threatening to ostracize others. Such behavior, which contradicts their first claim above and can hardly be characterized as caring, points to potentially important conflicts among women and to limits to women's caring. As Elizabeth Spelman (1991) and María Lugones (1991) argue, women's uncaring behavior toward one another is a key issue for feminist ethics to examine, and I return to this point later in this chapter.

Second, Gilligan's terms are problematic for several reasons. The term "ethic of care" implies that "caring ethicists" do not pay attention to considerations of justice, yet, as I have argued, the distinctive characteristic of this morality is that the agent pays attention to the context within which he or she applies considerations of *both* care *and* justice, and applies them with care for that context, including relationships between people, immediately and into the future. Thus, too, the term "ethic of justice" similarly supports a false dichotomy between justice and care. In addition to this problem, "care" itself is a word with multiple meanings and definitions,[2] while "justice" also has multiple-layered meanings. Users of these terms therefore need to be clear about how they are using them, but Gilligan never clarifies her meanings.

In this context I have coined the term "situated ethics," which I use to explore issues and debates prompted by Gilligan's notion of an ethic of care. This term parallels Haraway's "situated knowledge," which counters the claim that knowledge is impartial and context-free or context-independent, arguing instead that knowledge is inevitably, unavoidably produced within a social and cultural context, and that all knowers should therefore acknowledge the context within which they produce knowledge (Haraway 1988). I understand situated ethics to be characterized by the agent paying explicit attention to the particular situation and to the consequences for the relations between those involved, and by an absence of interest in making universal claims, although the agent may still appeal to abstract principles of both justice and care. Such an approach to ethics can only be considered to be (solely) gendered from a narrow Western/northern perspective, since cultures that are more collective and less individualistic than those of the West/north may also have more

contextual approaches to ethics (Kleinman 1995, on Chinese ethics; Kondo 1990, on Japanese ethics; and Collins 1996, on African American ethics).

Conversely, I use the term "detached ethics" to describe a morality that is characterized by the agent's attempt or claim to abstract universal principles from specific ethical decisions made in particular contexts (or to explain those decisions in terms of abstract principles). The same ideology—that a detached position is both possible and desirable—underpins both detached ethics and detached knowledge, as opposed to the claim made by proponents of both situated knowledges and situated ethics that pure detachment and "objectivity" are impossible.

I could seem to be contradicting myself here, since I am criticizing Gilligan for her use of dichotomies, yet using them myself. But the distinction between seeking detachment and accepting and acknowledging situatedness seems to me a more useful and fundamental dichotomy than the ones Gilligan uses. In the context of this reframing I now turn to issues arising in my research at St. Z's.

SITUATED ETHICS IN ST. Z'S

St. Z's was run by an order of nuns from Ireland, and a convent was attached to the side of the hospice. However, it was situated on the outskirts of a strongly Protestant town, which had resulted in some tension when the hospice and convent were first built in 1987. Other than one black British GP who attended the hospice to visit patients, the workers in St. Z's were all white, Western, and to a greater or lesser extent Christian. Most were women.

There are three main things from Gilligan's work that I applied to my fieldwork. First, in my records of conversations (field notes) and in my interview tapes and transcripts, I looked and listened for markers of moral reasoning such as "should," "ought," "good," "bad," "better," and also "fair," "unfair," "right," "wrong," "love," "care" (that is, considerations of both "justice" and "care"). I looked for these markers in what people said to me and to each other, in my own thoughts and feelings, and in the notes I took about these. Second, by listening for phrases such as "I mean," "you know," "I don't know," I listened for any difficulties people had in articulating their ethical positions. Third, I explored hospice workers' evaluations of care as self-sacrifice in relation to the three levels Gilligan uses to describe moral reasoning. I draw on these to examine some key aspects of my research practice including the negotiation of access, informed consent, reciprocity, and issues of representation.

Negotiating Access

Gaining access to a research site raised issues that illustrate significant differences between situated and detached ethics. In the decisions I made I was, on the one hand, inclined to do things that a proponent of detached ethics might consider unethical, but, on the other hand, I also placed greater restrictions on my actions than I would have had I adhered to detached ethics.

I had been volunteering at a hospice in Edinburgh for about eighteen months when I applied for access to do my fieldwork there, which was refused by the medical director. His refusal came in response to a letter I had written to the hospice's board of management, in which I had asked if it would be possible for me to meet and talk with them about my proposed research. I had given no details of what I hoped to do, nor was I given the opportunity to discuss it, but the medical director nevertheless said that it would be disruptive to the patients. What I had hoped to seek was permission primarily to do more of what I was doing anyway—talking to patients—although I intended to use this in a different way. In the role of volunteer, my talking to patients was seen as positive, useful, helpful, and certainly not disruptive. Indeed, at the same time as refusing me access to do my fieldwork, the medical director explicitly encouraged me to continue my work as a volunteer.

In refusing me access and arguing that research was disruptive to patients, the medical director appealed to considerations of care, and he applied general, universal rules of care and protection from harm along the following lines: research is disruptive; disruption is harmful; it is wrong to harm patients; therefore, it is wrong to do research with them. This is a very clear illustration of detached ethics, and it also illustrates that considerations of justice and considerations of care do not constitute a dichotomy in the way Gilligan suggests.

The medical director had not considered (indeed, was not aware of) the specific nature of my proposed research, nor the wider context of my relationships with patients and staff. He did not consider the consequences of his actions for these relationships, neither for me nor for those people with whom I had established relationships.[3] Even if, having gained access to do my research elsewhere, I had continued volunteering at this Edinburgh hospice, it would have been difficult for me to volunteer there and *not* think about what I was doing ethnographically, both in its own terms and also in relation to my experiences elsewhere. This meant that the refusal of access had consequences for my volunteering, and, given that some of the people with whom I had established relationships over a significant length of time were patients and therefore terminally ill, it was very likely that my relationships with them could not be continued, even if I returned to the hospice after conducting my fieldwork elsewhere.

In the event, I gained access elsewhere, and, although I visited the Edinburgh hospice a few times after completing my fieldwork at St. Z's, my connection with it and with the people there had been broken, not least because several of the people I had known had died since I had stopped volunteering there. Although we said goodbye to each other when I left, we lost time together as a consequence. I did not return to the Edinburgh hospice as a volunteer after completing my fieldwork, partly because my connection with the people there had been broken, but also partly because I did not want to create overlap or confusion with analyzing and writing about my findings from St. Z's. Thus, not gaining access to the Edinburgh hospice put an end to my voluntary relationship with the people there.

For a while after being refused access, I considered the possibility of continuing to volunteer at this hospice and doing covert research. I did not feel that this would

necessarily be unethical for two reasons. First, I did not believe that my research would be harmful to patients or indeed to staff, and, second, my interpretation of care for the patients differed radically from that of the medical director.[4] In the end, however, I decided against conducting covert research, not because I considered that this would be unethical, but because I was concerned that I would find the covertness too exhausting. I was also concerned that if I did covert research, I would ultimately have to justify myself within the dominant view of ethics, that is, in terms of detached ethics, when I came to submit my thesis, and if I were subsequently to seek publication in academic journals.

Reflecting on all this now, I think that I felt able to justify doing covert research at least partly because I felt that the medical director had shown a lack of trust in me and caring for me, and also, therefore, that he had been unfair to me, that is, that he had been neither caring nor just. For him, the context, including the relationships between me and other people, within which I had approached him to ask for access to do my research appeared to be irrelevant. However, it is possible that context *did* matter implicitly. Some years earlier another doctoral student had conducted research in this hospice, and her thesis had been quite critical (Mazer 1994). So her research—at least the written version of it—could indeed have been disruptive, although to staff rather than patients, and the medical director's refusal of access for my research could possibly have been related to that. However, I never discovered whether this was the case, and after I gained access elsewhere I did not think the question was worth pursuing.

While I was considering the question of whether to do covert research in the Edinburgh hospice, I applied to several other hospices for research access, eventually choosing St. Z's. I was not asked by St. Z's to seek formal approval to conduct my fieldwork, and I was given unrestricted access (at least ostensibly, although obviously tacit limitations would be in place). From a detached ethical position this could be taken to mean that I could speak to whomever I wanted and use the resulting material, together with that gained through my observations, as I wanted. However, for me, context, including relationships, mattered, and having unlimited access intensified my sense of responsibility and concern for the people there.

It can perhaps be taken as given that I felt a sense of responsibility and concern toward the patients in St. Z's; in any case, I will focus here on my sense of responsibility and concern for the workers. This operated partly on a general level: the managers of St. Z's did not know (any more than the medical director of the Edinburgh hospice) what my research involved, and I was concerned that they did not really understand the potential hazards of ethnography.[5] However, at least the managers, as "gatekeepers," had the option of granting or refusing me access, unlike the staff, who had no control over this. Yet the consequences of my research were less likely to be problematic for the managers than for the staff, who might not only find my fieldwork or my thesis upsetting, but might also find their jobs threatened as a result of my findings. I therefore felt an even greater sense of responsibility and concern for the staff of St. Z's, and will now move on to discuss how this affected

decisions concerning who to study and also raised questions for me concerning the meaning of the term "informed consent."

Informed Consent

In the early stages of my fieldwork, I hypothesized that the spiritual aspects of hospice care were to be found in the manner in which care was delivered, that is, the way in which caregivers provided care, rather than in the content of that care. However, as I spent more time in the hospice, I began to find this hypothesis more problematic and began to focus more on the content of care. Although it seemed to me that staff were generally very caring, I found it difficult to identify anything that seemed to me particularly spiritual as opposed to emotional or psychological. I wondered whether this was because the more spiritual aspects of care would necessarily be very intimate, for example, given on a one-to-one basis when the caregiver and patient were alone together, such as in the bathroom, and so I would be unlikely to witness them. I also felt that the taboo around open discussion of spirituality (evident even in this explicitly Christian hospice) meant that it was more likely that people would talk to me on a one-to-one basis than in the public spaces of the hospice.

I therefore decided to conduct individual taped ethnographic interviews in order to explore people's understandings of spirituality and the spiritual aspects of care in depth. However, since I was in some doubt as to whether patients were receiving more than very limited spiritual care, I felt that it would be wrong for me to raise the question of spiritual needs with them if I felt that neither I nor hospice workers were likely to meet such needs.[6] So I conducted tape-recorded interviews only with hospice staff. If patients raised spiritual or religious issues in (untaped) conversations with me, I followed this interest, but the decision I made not to tape-record interviews with patients means that my material on patients' perceptions is limited, and my thesis focuses more on hospice workers' understandings of the spiritual aspects of care.

This decision also illustrates the practice of situated ethics: I considered not only whether I had access, but also the consequences of my research for people in the present and the future. However, while my focusing primarily on staff resolved one ethical issue—concerning patients—it raised others concerning staff.

In the United Kingdom, when prospective Ph.D. students submit a research proposal to the Economic and Social Research Council, they are asked to discuss "any ethical issues" relating to their project. The same is true of applications to most funding bodies as well as for research on health services. This, of course, refers to ethics within the generally understood ethical framework, that is, the framework of detached ethics, which is how the dominant idea of informed consent is framed (Engelhardt 1996; Kleinman 1995). At the time of submitting my proposal, I duly discussed ethical issues within this framework, but, as I have indicated, I subsequently realized that for me abstract ethical considerations are *not enough*, and that situated ethics effectively subsume detached ethics.

Before going to St. Z's, and once there, I was careful to tell staff and volunteers what my research involved, as far as this was possible, given that ethnographic research evolves in the interaction between researcher/s and "researchee/s." After I arrived I was repeatedly asked (sometimes several times by the same person) "What is it you're doing again?," a question I always tried to answer as fully and honestly as I could. I asked all the people with whom I conducted taped interviews to sign consent forms, so I was "covered" ethically, that is, in terms of detached ethics. Nevertheless, I was very uncomfortable with whether I could really say that I had obtained *informed* consent from my "researchees."

In terms of detached ethics, it is enough to give an information sheet and have the consent form signed. If the person gives consent and if no deception takes place, it is, in effect, irrelevant whether the person "really"—that is, fully and completely — understands what is going to happen. The repeated question "What is it you're doing?" suggests that, although my "researchees" had read the information sheet on which I detailed the aims of my research, had had the opportunity to ask questions about it, and had signed the consent forms, they did not really understand what they had agreed to. I would argue that participants in—"subjects" of—ethnographic research do not (indeed, cannot) ever really understand the consequences of what they agree to since it is impossible to fully anticipate what one will reveal or how the researcher will use it. Indeed, when I first started my fieldwork, for much of the time *I* did not fully understand what I was doing or trying to do, in practice as opposed to theory, and if this was true for me then it was all the more so for those whose consent I sought. Having conducted this ethnography, and, as a result, being more aware of the potential of such research to misrepresent people, despite using their "own words," I am not at all sure that I would agree to participate in an anthropological study of my work situation, certainly not without having a great deal of trust in the researcher.

With those members of staff with whom I did not conduct interviews, issues of this kind were in some ways even more pronounced. Although I told people that I was there to do fieldwork and explained to them what my research involved, many of those with whom I interacted appeared to find it very difficult to recognize my presence as that of a researcher/ethnographer, not least because ethnographic research does not fit with the usual allopathic medical understanding of research. Indeed, it emerged that many staff made sense of me by thinking of me as a kind of volunteer, which was a recognizable role within the hospice. So, for example, when I was in the palliative care ward one Friday afternoon and planning to stay there into the evening, one of the auxiliary nurses suggested that I help at the children's drop-in in the early evening, since she had signed up to help after she finished her shift, but she had realized that she was unable to go after all and the drop-in would be short of helpers.

Staff's repeated questioning of me concerning what I was doing could be interpreted as stemming from their distrust of me, but generally I felt that their actions implied a great deal of trust. At times I felt they trusted me or confided in me too much, and I was uncomfortably aware of the potential for this trust to be abused, at

least within the framework of detached ethics, which makes it possible to claim that, having been given access and possessing signed consent forms, I can ethically use everything that I observed and was told.

Reciprocity

In practice, the care and trust I received from people at St. Z's generated in me a sense of reciprocal care. Sarah Hoagland (1988) argues against Noddings' (1984) unidirectional caring, or *agape*, as a model for caring relationships, arguing instead for *philia*, reciprocal care between equals. The professional caregiver-patient relationship is unequal, like that between parent/caregiver and child: in neither of these relationships will the cared-for reciprocate equally, if at all, nor can he or she be expected to.[7] Nevertheless, the caregivers in these asymmetric relationships still need to be cared for by someone else, and I would suggest that care between caregivers (that is, when a community of caregivers cares for one another, rather than the cared-for reciprocating for the care they receive) could be called indirect reciprocity.

Thus, in the Edinburgh hospice where I volunteered I felt cared for by the volunteer coordinator and the day hospice staff, in return for the care I gave to the patients, and I felt that the medical director did not care for me in this way.[8] At St. Z's, where I also felt cared for by many of the staff, I felt a reciprocal sense of responsibility. I cared about them, and I felt that I owed them something in return for their trust in, and caring for, me. My role as ethnographer prompted me to set limits to my research, and, in order to address my own discomfort with what sometimes felt to me their extreme openness, I deliberately attempted to draw attention to the fact that I was a researcher by taking out my notebook and pen and visibly taking notes while sitting in the nursing station, rather than going and sitting in the bathroom to do so (which I had been doing initially, so as *not* to make staff aware and self-conscious that I was taking notes on what was happening).

Some of the care I received highlighted broader issues about my position within the hospice. In her study of service industries, such as the airlines, Arlie Hochschild (1983) suggests that employers specifically seek out employees (frequently women, in the case of cabin crew) who already have the required (gendered) characteristics and then set out to develop these characteristics as work assets. This was something that clearly happened in St. Z's, and I was aware of it early on, using the phrase "talent-spotting" as a shorthand for it. Many student nurses came to the hospice on six-week placements toward the end of their training. At an early stage of their placement, managers seemed to make a decision as to whether they were the kind of nurses who would "fit" in to the hospice. Those who were identified as such were often approached at the end of their placement and asked to apply for posts in the hospice after their training was completed. Several of the nurses working there during the period of my fieldwork had been approached in this way, and St. Z's was their first (and only) job since training.

"Talent-spotting" also happened to me. I was repeatedly validated by both staff and managers in remarks such as: "What are you going to do next? You should work with people," or "You could be a counselor," or "Would you like to sit with D? I know you've built up a good relationship with her." This was both disconcerting, in that it drew my attention to how I too was being observed in my interactions with people (in ethnography, the researcher-researchee relationship is often two-way), and ironic, because it was important to me that my interactions with patients were noted and valued. I therefore felt reciprocal care toward those people (including managers) who validated me, yet at the same time I knew that the managers did not (explicitly) validate workers who, I also knew, would have liked to have been acknowledged.

The cynical interpretation of such comments is that managers were trying to "keep me sweet." But if that were the case, why me and not staff? Why did the managers not feel that it was necessary to validate their workers? Alternatively, they could have perceived validation of me as appropriate precisely because I was not a waged worker, and my presence there was not seen as my work (again, blurring the boundary between volunteer and ethnographer). But, whatever the reason, the point is that how I was and what I did, particularly with patients, that is, the "emotional work" (Hochschild 1983; James 1992) that I was doing, was not seen as *work*, but as innate, as "just how I am." This paralleled managers' perceptions of the emotional work of those nurses who managers characterized as people who "just have that gift," and who "gave without expecting to get back." Yet what was taken as "just how I am," was something I worked at; I was well aware of the emotional work involved in not being entirely myself. This is not to say that I was being false, but I was deliberately suppressing parts of myself, for example, by listening to people's opinions and, while possibly questioning them, not challenging them, and that took *work* (Treweek 1996; Young and Lee 1996).

Issues of reciprocity became more complicated because of tensions among hospice staff. In the early months of my fieldwork, I was not aware of tensions in relations between staff and management, and, even when I became aware of these, I chose not to explicitly focus on this area, thinking of it to some extent as background, which did not significantly impact upon spiritual issues for patients. It was only relatively late in my fieldwork, when people who were particularly unhappy began to express their unhappiness to me, that I began to think about the connection between spirituality and ethics, and to think that, even apart from the consequences for patients if staff were unhappy, staff-management relations also raised important ethical issues, and that these were also (therefore) spiritual issues.[9]

I cannot claim to have paid equal attention to all the workers in the hospice: I had strong links with most of the paramedical staff, and with some nurses and volunteers, but by no means with all, and my connections with the administrative workers and domestics and kitchen staff were the most superficial. This was predominantly owing to where, and with whom, I spent most of my time; but toward the end of my fieldwork I began to wonder whether my lack of strong connections with some nurses was to some extent because of the staff-management relations and the resulting (unspoken) questioning on their part: Could they trust me? Was I a management spy?

Those who told me how they felt about staff-management relations tended to be people who were close to leaving or retiring and/or those whose unhappiness was considerable. The confidences these people chose to share with me raise questions about their motives: Did they trust me to keep their confidences to myself, or were they trusting me to represent them and their views to others? When I checked with the people who were the most critical about management, whether I could quote (represent) their words, they all said that they wanted me to do so. The ethical implications of this, however, were far from clear. By explicitly representing these people's positions in my thesis, I would be, on one level, being fair to them. But, while those who were planning to leave would be unaffected by me making their point for them retrospectively, there are potential risks for those working in the hospice if the managers read my thesis and determine who said what to me. I discuss this further in the next sub-section, but before doing so I want to comment briefly on another response to this dilemma.

At an all-female session of the workshop discussed in the introduction I presented an early version of this chapter and raised the question of how I was to represent staff criticisms of their managers in my thesis, bearing in mind the very real risk that, however circumspect I might be, within the hospice individuals would probably be recognizable to one another. Some of the women at the workshop suggested that staff might perceive me (and, by extension, my research) as a conduit to management and a way of indirectly expressing their concerns and put forward utilitarian arguments, along the lines of the greatest good for the greatest number, for why I should include all this material in my thesis. These women were expressing detached rather than situated ethics, again suggesting that these two moralities are not necessarily gendered but are themselves situated, with the dominance of detached ethical frameworks within academic contexts probably fostering this response (compare Nicholson 1993).

Representing Research

According to Jaggar (1991: 99), "on the metaethical level, the goal of feminist ethics is to develop theoretical understandings of the nature of morality that treat women's moral experience respectfully but not uncritically." She argues further that if moral philosophers are to abandon transcendental approaches to ethics, they have no alternative but to start from, and to describe, actual moral experience. However, she points out that "no critical ethical theory can be satisfied with convention," but instead, it "must find a way of moving from description to prescription," and that this means facing some of the deepest problems in moral epistemology.[10]

Thus, to some extent feminist ethics are prescriptive, since feminist ethicists are motivated by a political agenda and seek to challenge canonical ethical theory. Gilligan's work is partly descriptive and partly prescriptive: for her, women should aspire to the post-conventional level of her ethic of care. Since even post-conventional morality is at least partly formed at a deep level, I think that one experiences one's personal ethical position as being unavoidably absolute, prescriptive, although it may still be open to negotiation. To move forward one needs to accept that other people's ethical positions are similarly absolute, and, through open debate and discussion, revise, develop and/or adapt one's own position.

The possibility of negotiation and revision is crucial both methodologically and ethically and affirms the importance of approaching ethics descriptively.[11] Thus, while I have my own ethical position, which agrees to some extent with that of some of the people in the hospice, I am trying to understand all their positions and not to judge them, although this is at times difficult, since moral positions are deep rooted and therefore powerful.

In practice I related most strongly to those women who were trying to care for others, while refusing the symbolic gender associations with self-sacrifice, that is, to women who seemed to me to be struggling to resist the conventional level of situated ethics and to move to the post-conventional level. However, I am concerned to do justice to the positions of all parties and not to represent that with which I have most sympathy as the "right way." In other words, I do not want to judge as morally inadequate those people who seemed to me to operate at the conventional level of situated ethics. In addition, as I have already suggested, people's morality is not purely internally determined but is powerfully influenced by their circumstances. Further, if people are to negotiate and revise their moral positions through dialogue with others, that dialogue must enable a range of positions to be recognized and respected. I would argue that all the workers at St. Z's were well intentioned, but that they were struggling with conflicting perceptions of the world, including the influence of their own socialization and dominant (moral and gender) conventions. My concern to be fair and just toward these people is interwoven with my care and concern for them and my sense of responsibility toward relationships between people there, which could be damaged by what I chose to write about. This further illustrates the consequences of situated ethics for writing about fieldwork.

Feminist research methodologies hold that researchers should not use the words of research participants in isolation, that is, as raw material to support or illustrate the researcher's arguments, but should locate them within the context of the conversation or interview, and also within the wider context of the situation of the person who is speaking. This theoretical or methodological point is rooted in ethical considerations—to do justice, to avoid exploitation—but it can also lead to ethical conflicts.

In a small institution like St. Z's, contextualizing a quotation with details about the conversation, or about the institutional position or personal attributes of the speaker, would enable others within the institution to identify that person. The question of trust and confidentiality was already an issue in the hospice. For example, X talked to me about her discomfort, having confided in Y, at subsequently hearing her (X's) words repeated back to her by Z. If I were to give any details about X or about what she was talking about, she could easily be identified. So, although I have a signed consent form from X "covering" the taped conversation in which she talked about

her discomfort, and although she repeated her consent for me to write about this in my thesis when I checked with her later, there remains a moral tension for me concerning how, and if, I represent such evidence, which relates to my sense that I have a wider, ongoing responsibility for the relationships between the people in the hospice.

A proponent of detached ethics would probably argue that a researcher has met her ethical obligations as long as she has done her best to disguise the particular research site (in this case, the hospice) and the particular individuals to whom she refers (by using pseudonyms). But this can only protect those people to a certain, limited extent, that is, from being identified by outsiders, and implies disregarding considerations of the impact of the written version of a study on future interactions between them.

It is also worth noting that the use of pseudonyms raises language-related problems, since names have meanings. In the west of Scotland names are markers of Catholicism and Protestantism, and people can almost always be placed by their surname, often by their forename. Moreover, several names (especially saints' names) were shared among several women in the hospice, and people therefore distinguished between these women by calling them by their first name and surname (for example, Betty Smith, Betty Jones). This use of full names happened frequently, since a particularly striking thing within the hospice was how all the workers and volunteers regularly used each other's names in conversation or greeting. Also, the hospice and the wards within it had saints' names, which had been chosen for their particular meanings, that is, the concerns for which particular saints are patrons, and using pseudonyms changes those meanings.

CONCLUSION

As my discussion shows, the moral orientations, expressed both by the people with whom I interacted in my fieldwork and within my own decision making, were broadly similar to those described by Gilligan in terms of (different levels of) an ethic of care and an ethic of justice. However, the distinction between these moral orientations was more subtle than her dichotomies between care and justice convey; indeed, considerations of care and considerations of justice were frequently inextricably intertwined. Consequently, the value of broadening concepts of morality in line with Gilligan's ideas is greatly enhanced by recasting her moral orientations in terms of what I have called detached ethics and (the various levels of) situated ethics. With this reframing Gilligan's work has proven helpful in reflecting on my own moral choices and also for thinking about tensions between people in St. Z's.

I have also argued that, although women may *tend* to adhere to one moral orientation and men to the other, these orientations do not map directly onto gender. They might be more usefully thought of as symbolically feminine and symbolically masculine and linked with associated perceptions of truth and knowledge. Combined with Gilligan's notion of three levels of moral reasoning, especially her collaborative reworking of movement between levels, and with the emphasis on context in the notion of situated ethics, this highlights how women's (and men's) struggles with moral issues also entail struggles with dominant social conventions. People's subjectivities and understandings of the world shape their various ethical positions, resulting in different perceptions of need, right, wrong, guilt, and blame.

NOTES

1. Drawing on Nancy Chodorow's (1978) theories concerning the consequences of woman-centered childrearing, Gilligan argues that her work illustrates how women tend to fear separation and abandonment, while men fear closeness, and she claims that men and women differ widely in how they delineate their selves. Gilligan claims that the male self is commonly constituted by difference and separation. Men see themselves as central and see the world as relating to them. Their goal is individual achievement, so involvement with others qualifies their identity, rather than leading to its realization. They therefore fear intimacy and seek to break out of situations they perceive as smothering. Conversely, Gilligan argues that women understand the self as constituted by connection, they fear isolation, describe themselves in terms of their relations with significant others, are more concerned with both sides of an interdependent relationship, and quicker to recognize their own interdependence. They believe that hierarchical relationships and isolation of the self lead to aggression. Thus, Gilligan claims, each sex perceives a danger in relations with others that the other sex does not: men in connection, women in separation. She concludes that, because of this, men and women have diametrically opposed tasks in their transition to adulthood (and/or moral maturity), that is, that, as Daphne Hampson (1996: 94) puts it, "men need to learn to be a self-*in-relation*; women . . . to be a *self*-in-relation" (her emphases). Arguably, also, Kohlberg's post-conventional men are *conforming* to social norms for men, by increasing their detachment.

2. In particular, the association between care and the "private" realm is not always questioned (see for example Noddings 1984). With its provision of intimate care for strangers, nursing straddles, and potentially challenges, the supposed public-private divide (see, for example, Bowden 1997).

3. This is not to say that if he had considered these issues he would necessarily have given me access; the point is that he did not see them as relevant to his decision.

4. It is interesting to note here that when discussing this question with my two Ph.D. supervisors, my female supervisor (a social scientist) was sympathetic with my position and my male supervisor (a nurse) sympathized with the medical director, although obviously it is not valid to generalize from this to all women and men.

5. I am thinking here of the risk of "hatchet jobs" that people who grant access for "fly-on-the-wall" documentaries sometimes experience; indeed, at one point one of the doctors commented that I was a "fly on the wall," and I tried to explain the distinction between my work and such documentaries but without much success.

6. I was not in a position to meet them, not only because of my lack of qualifications and experience, but also because of my intermittent presence in the hospice and the consequent lack of continuity.

7. Although patients, particularly female patients, may often care for their professional caregivers and/or indeed for their fellow patients.

8. Indeed, the voluntary sector well recognizes the need to care for volunteers, if only on the very pragmatic basis that such care is necessary to retain them.

9. I also then began explicitly to widen my exploration of "spiritual aspects of care" to consider caregivers' spiritual needs as well as those of patients.

10. Also see Hoagland's (1988) ethics for lesbians, and Hampson's (1996: 96) claim that recent feminist thinking is "not only descriptive . . . but . . . also legislative."

11. My approach closely parallels Bowden's (1997) study of caring.

Conclusion

Gillian Rose

The chapters in this book cover a wide range of research projects, and their topics are correspondingly diverse. However, as Liz Bondi demonstrated in the introduction, they share a number of themes that are part of a wider feminist project concerned with the politics of knowledge production. They were all written as part of what its participants characterized as a (particular kind of) feminist academic practice: a collaborative, reiterative, and supportive process of reading and writing that tempered the more conventional academic model of sole authorship (Feminist Geography Reading Group 2000). All these chapters also engage with a number of interpretive problematics concerned with the relations between knowledge and subjectivity. All assume that knowledge is embodied; that is, that knowledge is produced by corporealized subjectivities. All assume that those bodily subjects are positioned in extraordinarily complex articulations of identity, including gender. And all assume that those identities are relational; we are always located in relation to others, not least for academics to those we research. While each chapter can address only some aspects of these assumptions in any depth, it is their shared pertinence to all of them that also gives coherence to this volume.

The spatialized language with which these claims about knowledge production are made—talk of bodily boundaries, situated knowledges, and dis/connections—is now so familiar that it is perhaps difficult to remember that this has not always been the vocabulary with which feminist geographers have addressed the importance of spaces to the production of knowledge. Feminist geography first began to emerge into publication in the mid-1970s. That geography needed feminism was evidenced in two ways in this early work: first, geography to date had paid no attention to women, and, second, the discipline had paid no attention to what were perceived as "women's issues." In an important analysis of why this had been the case, Janice Monk and Susan Hanson (1982) drew on another spatial analytic: that